THE UNIVERSITY OF ALBERTA

HOW CAN WE UNDERSTAND THE LIFE OF ILLNESS?

by

CAROL T. OLSON

(C)

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled HOW CAN WE UNDERSTAND THE LIFE OF ILLNESS? submitted by CAROL T. OLSON in partial fulfilment of the requirements for the degree of DOCTOR OF PHILOSOPHY in DEPARTMENT OF SECONDARY EDUCATION.

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ABSTRACT

This research question dwells in my life: "How can we understand the life of illness?" The question emerged in childhood, when my oldest brother, Eddie, and my baby sister, Grace, died of kidney failure and related causes. When I was ten years old, my mother told me I had kidney failure too. During my teen years, my younger sisters, Joy and Crystal, and I were frequently in hospital as the disease progressed. Crystal died when I was in high school. The following year, 1969, my older brother Arthur experienced the sudden collapse of his kidneys with Hong Kong flu and began dialysis on the artificial kidney machine. Joy and I began dialysis two years later. Our years on dialysis together ended when Joy and Arthur died in 1983. My father died from a heart attack in 1979. Yet the meaning of their lives is not primarily that they died but how they lived. How ought we to live? Though this research is completed, the question is new each morning.

The technology of medical care is part of the research question too. Medical technology sustains my life. But technology itself has no life—no soul that suffers pain and abounds in hope. And so technology is mute about the pain it requires of us, the hope it inspires in us, the life it gives us. The silence of technology becomes a question within us: "What is life that technology is not sufficient for life?" This question turns us to what is beyond us, to God, the search for what is good in the re-search of daily life.

How could I research the life of illness in a way that would help understand how one ought to live? Gadamer writes that understanding is always application, a form of action. Therefore, I searched the actions of those who live in illness and with illness to let show their understanding. The method for my research was hermeneutic phenomenology, the action of reflective reading, interviewing, and writing. Excerpts from literary texts were engaged in hermeneutic reflection with a medical doctor, a nurse, a chaplain, and a family member. In this way, the life of illness was researched through the community of illness.

In all these actions, I could not theorize myself out of the pain and the hope, the life of illness. I stand in illness in my research before God, one of the world in pain and hope. I want

to live in understanding. I want to learn how one ought to live through illness, even through the grief of pain. The method of finding the themes of pain and hope is reflection: thinking from the heart of mute experience to come to the heart of the written word. Literary texts show the silence of illness through the voice of the individual, reverberating with the heart of one's experience, shared by all. Still the words of the shared understanding — themes, are not easily articulated. Whereas the literary author lets the themes rest in the writing of story and fiction, the researcher searches for the words of the themes as they are shown through description and dialogue in the literary text, in interviewing, and in the research writing. Explanation would stop the question, "How ought we to live?" but themes reveal possibilities for living in this question until the themes themselves become open to deeper understanding.

The deepest understanding that this research has yielded is a quiet saying, the theme: "The good of understanding is action, is love (care)." In illness, there is no life in us other than the love of God for us. There is no life for us other than the love of family, friends, and community; and our love for them. Some live to love the multitude, like Mother Teresa. But love is experienced in the individual. So I could not suggest appropriate action for different situations of illness: the good of understanding, the action of love—God's love, is you.

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Chapter I

WHAT IS AT STAKE IN THE RESEARCH QUESTION?

> The more fundamental a question, the more it demands that the self-understanding of the question be itself examined and interpreted.[1]

Critical Context of the Question

All of humanity are children of technology. All through history, humanity has made itself technologically. The peasant's life is harnessed to the plow he made. The shepherd's life is managed with the staff he made. Our life, too, is conjoined to the tools we inherit and invent. And these tools that we make, ever more diverse and complex, re-make us.

All our making empties us; our life is poured into the works of our hands. We are dis-spirited; technology is the spirit of the age, our immortal body. For example, the ruins of other civilizations are tributes to their makers, effigies of the human will to immortality. But we pioneer the making of our self in our corporeal image—the respirator, the artificial kidney machine—life after death on earth. Thus, the world and everything in it, including our self, appears as though we made it. We are set apart from technology's other children: we are technology's chosen people. We see a use for every-thing. We see nothing more than use-value in any-thing. So we cling to what we have made, even the tools of our own destruction, and we believe in what we can make. Technology is us. What will become of us?

I am victim, I am victor,
For death will win its waiting game.
Momentarily I have tricked her
Fanned life's fading flame.

But life is worthwhile living,
Uncertain day to day
When you can be doing, giving,
When the world heeds what you say.

Leave me without purpose;
Take my self-esteem;
As well to leave me lifeless
Than only alive on a machine.[2]

Many of technology's chosen people have already fled, like chirping lemmings, into the abyss. Some of us stopped at the edge of the cliff. We have re-turned. We come, raving fluently like Nietzsche's madman, "Whither is God... We have killed him—you and I."[3] We must speak this way: we have seen the abyss. And, we come, speaking haltingly, our words breaking under the awesome silence of each sacred breath. We must speak this way: we have seen the "bright morning star."[4] Either way, we come with empty hands. We offer our being—the abyss and the star, origin-al measure of the measure of technology.

Personal Context of the Question

I am one of technology's chosen people: my life is maintained by dialysis. Dialysis is the technology for washing the blood when organic kidneys die. Is dialysis only this? More than this? Even when we consider dialysis strictly as a relationship with a machine, dialysis is already us.

> I'm only 32 years old. Yet, in terms of dialysis, I'm a grandfather. At least, that's the way I feel when I look back on the fourteen years I've been friends with a kidney machine.[5]

> I could never take a vacation from the machine I married till death do us part.[6]

> The journey through the years with a technological parent is a human journey—dependence on the machine, rebellion from the machine, oneness with the machine.[7]

But dialysis is not strictly a relationship with a machine. Dialysis is a relationship with others—doctors, nurses, family, friends. And through all this, dialysis is a relationship with life.

> *Recollection of 1972.* I asked the doctor for an innovation which would make life easier.
> "You're never satisfied," he said. "If I give you what you ask for, you'll ask for something more."
> I agreed.
> "But this is artificial life support!" he said. "What do you want out of it anyway?"
> "Everything."
> He stared at me for a moment, then hurried away. All evening, I repeated to myself, "Everything. I want everything."[8]

> I asked for all things that I might enjoy life.
> I was given life...[9]

Year by year, doctor and patient encounter each other. Yet each life is hidden from the other behind tests, statistics, protocol; separated from the other by the technology that brings us together.[10]

> The nature and importance of our relationship to one another is a core issue in every society, system of ethics, and religion. Dialysis and transplantation have re-emphasized how central it is to medicine as well. This has occurred in a period of generalized crisis over whether and how an advanced modern society like our own can achieve a more trusting, intimate, inclusive, and transcendent form of solidarity.[11]

The crisis: we have forgotten how to listen and to speak with each other. But *what* have we forgotten?

Linguistic Context of the Question

Karatheodoris,[12] whose theorizing is guided by the work of the ancient Greek theorist Heraclitus, believes that speech is essentially a moral responsibility of community members. The ancient Greek responsibility for community was called forth in the image and in the activity of caring for the hearth-fire: the hearth-fire which provided warmth and togetherness for the members of the family. Caring for the hearth-fire was a caring for the community, the collective family. This life-force, caring, the ancient Greeks called *logos*. So *logos* was not inherent in any fire but in their care and use of the fire they kept at the center of their dwellings, at the center of their lives, in the hearth. Care transformed the fire and those who tended, used, and shared it. Thus, *logos* is the calling together of community (the fire that gathers individuals together in care for each other) and the community that is called (those who are gathered in care for the fire).

The most profound attunement to *logos* is shown when we near the fire and are scarred by it for the good of an other. This is our rational character; "the verb, *charassein* (Gr), from which character is derived, means 'to scratch,' 'to scar,' or otherwise mark. Those, then, who have suffered the ordeal of nearing *logos* bear the scar of rationality."[13] For example, we still

speak of a face having character. Character is born of care: one who cares (Gothic from Gr. *kara*, "sorrow")[14] sorrows for another, bears the sorrow of another. We say that the face having character is lined with care. [15] Care as the rationality (L. *ratio*, reason)[16] of community life was given to the ancient Greeks as the possibility they must thoughtfully choose for community life to continue. At the same time, the rationality of care was given before thought, in self-forgetfulness at this moment, as when loving parents respond to the needs of their infant son or daughter, often before the child cries. To belong to *logos* is to belong to each other: "listening not to me [the speaker] but to the *logos* it is wise to agree that all things are one."[17]

To dialogue is to speak and listen to each other in the light of *logos*. To speak is to (re)direct conversation towards *logos* as that which shows *logos*. To listen is to hear not merely the speaker but rather to "sustain yourself in hearkening attunement [to *logos*]."[18] So, to understand something in the light of *logos* is to presuppose an attitude of care for it and for the community that shines through speech and silence. For example, the attitude of care is both hidden and revealed in commonly used medical terms such as cardiology, nephrology, neurology. The suffix of each of these terms derives from *logos*. Thus, cardiology means to speak about—care for—the heart in a way that listens to—cares for—the meaning of the heart in the life of a human being, in the life of a community.

Logos joins our separate lives into a collective endeavor by calling each one to a personal commitment to care for the good of each one. "It is not in being attentive to the speeches of men, but in heeding our calling, that we achieve the sort of agreement that collects all things."[19] For example, 'hospitality' began as an expression of the ancient Greeks' personal and communal commitment to care for wayfaring strangers.[20] The stranger was welcomed as a friend would be welcomed. Each house was built with a room (Gr. *hospitalia* or *hospitalium*) for the stranger. Thus, the stranger was provided for in the physical structure of the community. But the stranger was truly a guest in the home—the heads of the household *became* the host (Gr. *hospis*) and hostess (Gr. *hospita*) as they invited the guest to share the family

meal. The ancient Romans provided for strangers in a similar manner. Private hospitality gradually extended to public hospitality but 'hospital' derives not from its public nature but from a reference to the guest (L. *hospitalis*). An ancient Greek and Roman tradition, *tessera hospitalis*, reveals the bond that developed between the stranger-guest and the hosting family. It was a medallion which guest and host divided and kept as a token of lasting friendship, not only during the lives of the friends but during the lives of their posterity. (The sign of a broken friendship was the breaking of one's part of the *tessera hospitalis*). Provision for the stranger was the *logos* of community life.

What can a human science researcher in our technological society learn from Heraclitus about "heeding our calling"? Many human science researchers forget their calling—forget their indebtedness to *logos* for illumining the things which science analyzes. Heraclitus warns that *logos* "escapes men's notice because of their infidelity."[21] Infidelity to *logos* results in scientific investigation which is alienated from communal being. Perhaps doctors and patients have forgotten how to listen and to speak with each other because we have forgotten *logos*, the origin of our collective life; we have forgotten *logos*, the origin of our rational character.

Purposeful Context of the Question

The re-search question, How can we understand the life of illness? is not primarily a question of method (*How* can we understand?) but a question of the heart (How can we *understand*?). How can medical and surgical doctors, nurses, patients, family and friends listen to and speak with each other about our experiences of illness in such a way that the speaking and listening re-collect *logos*, the origin of community, the origin of our relationship to each other? The question of method asks how we can speak the lived quality of the experience of illness. This question relies for its meaning on the question of understanding, How can we live the quality of life everyday so that our speaking can truly be "a direction for faithful speaking"?[22]

Logos calls us first, not to an analysis of *what is* but to an individual responsiveness to *what is*. The purpose of this study, therefore, is to understand how we are implicated in the situation where a person is ill, or, I am ill. Our belonging to community is a fulfillment of individuality: Because he or she is ill, I..., or, Because I am ill, I.... We seek to understand illness, "not just to know it better, but in order to know how we ought to live."[23] This is the good of understanding. How can we recognize the good? In Chapter II, we begin our research by asking, "How can we *understand*?"

Notes

[1] David C. Hoy, *The Critical Circle,* (Berkeley: University of California Press, 1978), p. 49.

[2] Samuel B. Chyatte, "To my fellow patients in the certain knowledge that life is more than survival," *Rehabilitation in Chronic Renal Failure,* ed. Samuel B. Chyatte, (Baltimore: Williams & Wilkins Co., 1979), Dedication page. Chyatte was a medical doctor on dialysis who died in 1979.

[3] Cited in Heidegger, *The Question Concerning Technology and Other Essays,* (New York: Harper & Row, 1977), p. 59.

[4] The full quotation is from Revelations 22: 16b, where Christ speaks, "I am the root and offspring of David, the bright morning star."

[5] Bill Blackton, "We Were Pioneers," *NAPHT News,* (November, 1979), p. 18. NAPHT is an acronym for National Association of Patients on Hemodialysis and Transplants.

[6] Michael Olmsted, "Some Thoughts of a Kidney Disease Victim," *NAPHT News,* (January, 1981), p. 7.

[7] Carol Olson, Technology's children, (Class assignment for Ed. C.I. 652, Pedagogical Theorizing, Dept. of Secondary Education, University of Alberta, January, 1982).

[8] Ibid.

[9] Anonymous poem, cited by June Crowley, "Editor's Notebook," *NAPHT News,* (November, 1977), p. 3.

[10] Representative critiques of modern medicine include: Ivan Illich, *Limits to Medicine: Medical Nemesis, the Expropriation of Health,* (London: Boyars, 1976), a critique of the "medicalization of life," for example, the hospitalization of birth, death and the common cold, and the analgesic avoidance of pain and difficulty; R. Mendelsohn, *Confessions of a Medical Heretic,* (New York: Warner Books, 1979), an allegorical critique of medicine as a religious cult, with a plan for reform, briefly described in Chapter III of this research; A. Allentuck, *The Crisis in Canadian Health Care: Who Speaks for the Patient?* (Don Mills, ON: Burns & Machearn, 1978), a critique of the abuses of medicare; M. Shapiro, *Getting Doctored: Critical Reflections on Becoming a Physician,* (Kitchener, ON: Between the Lines, 1980), a critique of

medical education.

[11] Renee Fox & Judith Swazey, *The Courage to Fail: A Social View of Organ Transplants and Dialysis*, (Chicago: University of Chicago Press, 1978), p. 380.

[12] Stephen Karatheodoris, "Logos. An Analysis of the Social Achievement of Rationality," *Friends, Enemies, Strangers: Theorizing in Art, Science, and Everyday Life*, ed. Alan Blum et.al. (Norwood, NJ: Ablex, 1979).

[13] Karatheodoris, p. 211.

[14] Ernest Klein, *A Comprehensive Etymological Dictionary of the English Language*, (New York: Elsevier, 1971), p. 114.

[15] Gordon McIntosh, Personal communication, September, 1982.

[16] Klein, p. 618.

[17] Heraclitus, Fragment 50.

[18] Heraclitus, Fragment 50.

[19] Karatheodoris, p. 213.

[20] Victor Robinson, *White Caps: The Story of Nursing* (New York: Lippincott, 1946), pp.9-11, 13. Robinson describes hospitality and the development of hospitals from ancient times to 1946.

[21] Heraclitus, Fragment 63.

[22] Alan Blum, *Theorizing*, (London: Heinemann Educational Books, 1974), p. 132.

[23] Max van Manen, Personal communication, March, 1984.

Chapter II

THE QUESTION OF UNDERSTANDING

By thinking comes to mind
the longings of my heart[1]

How Can We Understand?

How can we understand what belongs to *logos*, the origin of community, the origin of our relationship to each other? The ancient Greek theorist, Heraclitus, was certain that his message, "All is one," belonged to the origin of community. The truth of the ancient Greek sense of certainty shines through history in the example of the peasant whose life is harnessed to the plough he made. This sense of certainty is called forth by the rhythm of seedtime and harvest, cold and heat; grain in abundance, grain wanting; child born, child dying. The life of the peasant is the soil—from dawn to dusk, from dust to dust. Yet a question wells up through the certainty of the life called forth for and by the peasant's life: "Is there more to life than this?" The ancient Greek theorist knew this question, the question that called forth theorizing. "Is there more to life?" is another way of asking, "What belongs to *logos*, the origin of community, the origin of our relationship to each other?"

Technology's chosen people are certain only of the resource-fullness of every-thing. The meaning of any-thing is only its use to us. This is our life.[2] But we are exhausting the resourcefullness of everything, and still the grain is wanting, still the children die. Is there more to life for us?

To search through the question, "Is there more to life for us?" we must suspend—"bracket"[3]—our certainty that everything is only resourceful so that we might experience life anew. Bracketing our technological certainty is the starting point for this re-search.

Hermeneutical Phenomenology

> 'Phenomenology' is a name which is mainly used to designate a movement in the social and human sciences which has as its primary objective the direct investigation and description of phenomena as consciously (i.e., pre-theoretically) experienced.[4]
>
> Hermeneutics may be defined as the science of interpretation, or as the phenomenology of social understanding.[5]

Hermeneutical phenomenology is the dialectical understanding, "All is one". On the one hand, we are woven into the fabric of life. Merleau-Ponty expresses this understanding of experience when he writes, "he who sees cannot possess the visible unless he is possessed by it, unless he is of it."[6] On the other hand, "Understanding begins," writes Gadamer, "when something addresses us."[7] The phenomenon addresses us when it lifts itself out of the pattern in the fabric of everyday life and "shows itself in itself."[8] This understanding of dialectic is exemplified by van Manen, an educational theorist, who writes that the phenomenon of childhood calls us to choose pedagogical theorizing as a way of life which "orients us to the flesh of the world, as Merleau-Ponty poetized, to the intertwining, where I am not *with* the child, not *in* the world, but where I *am* the child, the world."[9] "Intertwining" is possible because the phenomenon of childhood addresses us uniquely in the person of each child we meet. Through the oneness of the intertwining we experience more deeply our separateness, as when a child does not understand the instruction we had planned specifically for him or her. We respond in a manner called teaching when we experience the child's misunderstanding and so, are enabled to lead the child out. Our intertwining attunes us to our separateness; our separateness enables our intertwining.

This dialectic is further exemplified by our experience of language. We say, "The sun is setting," though our day is setting and the sun is fixed. The silence of a day that is spent rests in this idiom as does the promise, "Tomorrow is another day." Language is not so much a resource for speaking (a vocabulary list) as a source for speaking (a well-spring). Each day brings new experience that is centuries old. As we transform the day into our life by the way we live, so we transform the experience into its meaning by the way we speak. The words on the

vocabulary list become a well-spring of meaning for us. This unique experience of the day and its words opens up to us a dimension of language which hearkens back to centuries old communal experience, while welcoming the not-yet-experienced. We wait for language, and language waits for us.

We live this dialectic when we express our response to the questions life addresses to us in specific situations with speech and silence, labor and rest, worship and praise. And yes, with research. The phenomenon of illness addresses us in this research. How can we express our response to the phenomenon of illness?

Expressing Our Response to Illness

There are two main ways of expressing our response to the phenomenon of illness. One way is to try to control illness technologically by making it predictable. A vehicle of technological control is *explanation* which binds everything in an absolute order. For example, we explain the progression of a disease and the effects of a medical intervention. When we explain, we stand apart from the phenomenon and observe the order.[10] Explanation has provided answers to many problems, yet explanation does not help us to know the question, "Is there more to life for us?"

The finality of explanation belies the mystery of the intertwining and our participation in this mystery: through all our experiences, each of us is uniquely enmeshed in the fabric of life. For example, two people with the 'same' disease respond differently to the 'same' medical intervention. *Description*, rather than explanation, 'speaks' our experience of living the phenomenon of illness. When we describe, we do not invest the phenomenon with meaning. We open ourselves up to the idea which inhabits the phenomenon, the idea which makes the experience of the phenomenon intelligible to us. "An idea," writes Merleau-Ponty, "is not the contrary of the sensible [phenomenon]," it is "its lining and its depth."[11] W.H.Auden shows that the idea comes to us in visible, tangible experience in his poetic description of what it is like to be in a surgical ward.

They are and suffer; that is all they do;
A bandage hides the place where each is living,
His knowledge of the world restricted to
The treatment that the instruments are giving.

And lie apart like epochs from each other—
Truth in their sense is how much they can bear;
It is not talk like ours, but groans they smother—
And are remote as plants; we stand elsewhere.

For who when healthy can become a foot?
Even a scratch we can't recall when cured,
But are boist'rous in a moment and believe

In the common world of the uninjured, and cannot
Imagine isolation. Only happiness is shared,
And anger, and the idea of love.[12]

In contrast to a lawlike explanation about the pain that accompanies surgery, Auden's poem opens up a world of shared experience. We participate in the truth of the poem: the silence that gives voice to each word, each phrase is our silence, our "mute experience."[13] As we enter into dialogue with Auden's poem, we begin to speak the silence of our experience. "For who when healthy can become a foot?" The whole body, a foot. The whole foot, pain. There is no other world. I am the foot-in-pain, waiting for the next fix that will move this foot, this pain, out there, while I remain here, still conscious that a foot-in-pain hurts somewhere. My only thought, a prayer that this fix will last the four hours until the next fix. My religion, my time—my life—bound up in the foot-in-pain, here or there. Lord, keep it out there. The mute experience of the foot-in-pain that pre-dates the reading of the poem becomes articulate when we read the poem. As the poem remembers in us our solitary experience, it confirms in us our solidarity with our community. Our interpretation of the poem is the poem's interpretation of us.

As the poem articulates for us and in us an experience of surgery, the poem asks for continued reflection in its light, and we become ready to read the poem though we may never see it in print again. In this way, we stand under the poem that understands us. Hunsberger writes, "When a reader gains insight and a broader, clearer vision, and is able to see the patterns and the wholeness, that understanding becomes a part of who the reader is and how

that reader relates to others."[14] We learn to live. Merleau-Ponty writes, "Life becomes ideas and ideas return to life."[15] Phenomenology expresses this "reversibility" ("always imminent though never realized in fact")[16] through dialogue.

Experience as Dialogue

We search for the future through dialogue with what is past. We do not recall events that are over. Rather, our experience lives in us, making us what we are.[17] An experience is a moment in which what belongs to *logos* 'speaks.' Gadamer writes,

> Experience is a matter of multisided disillusionment based on expectation; only in this way is experience acquired. The fact that experience is preeminently painful and unpleasant does not really color experience black, it lets us see into the inner nature of experience.[18]

Something is not as we had expected. For example, we expect to use specific tools to facilitate our daily existence. Tools are transparent in use, extensions of ourselves. [19] The hammer exists for us in the pounding of the nail. Though we grip the handle of a hammer, we feel the clang of its head on a nail. But suppose we expect to use a hammer and find it broken. "Breakdown,"writes Heidegger, "momentarily lights up the being of tool *as* tool." [20] Breakdown asks for dialogue. Similarly, our own breaking asks us what wholeness is. The foot that is healthy does not question us nor do we question it; we simply use it to walk and rest. The loss of this foot—injured or amputated—changes us. There is truth here, which the walking foot, the resting foot, could not teach us. There is pain here, the pain of brokenness. This pain, Gadamer calls the "inner nature" of experience.

Gustave Thibon brings to speech the negativity (pain) of past and present experience in dialectic with the positivity (hope) for the future. Our future is our heritage.

> You feel you are hedged in; you dream of escape. Do not run or fly away in order to get free: rather dig in the narrow place which has been given you; you will find God there and everything. God does not float on your horizon, he sleeps in your substance. Vanity runs, love digs.[21]

"Love digs." So we repair our broken tools, preparing a future for ourselves as we use them.

Our suffering and rejoicing in our work is hope in action. In this resoluteness of hope shines the promise of our future—*our* future because we live in community. To live in community means to speak and listen to each other. The individual responds to the question of the other, ready to give his or her world in speech and silence, ready to listen to—to welcome—the other who shines forth in his or her speech and silence.[22]

A personal-communal tradition streams through each individual. The voice of each individual is "bound to the mass of [his or her] own life as is the voice of no one else."[23] Each individual speaks from experience. Speaking from experience is "not like the butter on the bread;" it is "the expression of experience by experience."[24] Thus, to speak of experience is really to listen to experience. To listen to another individual is to participate in the truth of what he or she says. Understanding is a participation, "a participation in the stream of tradition, in a moment which mixes past and present."[25] The moment of participation joins the individual to his or her neighbor as the individual speaks in integrity, and listens in the manner of one who is oriented to the future, one who would be taught.[26] Thus, understanding is a community of shared meaning sustained by the integrity of the individual in conversation, the enabling of dialogue. Through dialogue, we re-turn to our experience in anticipation of our future. Through dialogue, we commun-icate with each other.

Logos teaches us to speak, to listen. *Logos* is our teacher. When we open ourselves up to *logos*, our attitude is unlike that of the researcher whose parameters for meaningfulness are control and replication. Our openness to *logos* is a dialectic of questioning and being put in question, speaking and listening. To dialogue is to listen to and to speak with our teacher, as our teacher is presented to us in the sound and silence of strangers and friends, work and play, wind and waves.

How can we understand? "The more we search, the more we search," Smith writes. "And it is the searching, the trying, the attempting, which keeps speaking... alive."[27] "How can we understand the life of illness?" is another way of asking, "How can we dialogue with illness?" Chapter III explores how two modes of theorizing put in question by Blum, a

sociologist, help us to understand the life of illness by enabling us to dialogue with illness. We "keep speaking alive" by theorizing and by thinking through theory.

Notes

[1] Ghada Daabous, "Good-bye, My Village," (Mississauga, Ontario: World Vision International, 1984).

[2] See Martin Heidegger, *The Question Concerning Technology and Other Essays*, (New York: Harper & Row, 1977).

[3] Edmund Husserl, "Phenomenology," *Realism and the Background of Phenomenology*, ed. R. Chisholm, (New York: The Free Press, 1960), p. 131.

[4] Max van Manen, "An Experiment in Educational Theorizing: The Utrecht School," *Interchange*, 10 (1978-79), 49.

[5] Max van Manen, "Linking Ways of Knowing With Ways of Being Practical," *Curriculum Inquiry*, 6 (1977), 213.

[6] Maurice Merleau-Ponty, *The Visible and the Invisible*, (Evanston: Northwestern University Press, 1968), p. 134.

[7] Hans-Georg Gadamer, *Truth and Method*, (New York: The Seabury Press, 1975), p. 266.

[8] Martin Heidegger, *Being and Time*, (New York: Harper & Row, 1962), p. 49.

[9] Max van Manen, "Edifying Theory: Serving the Good," *Theory Into Practice*, 21(1982),49.

[10] See Merleau-Ponty, "The Intertwining—the Chiasm," *The Visible and the Invisible*, pp. 139-155.

[11] Merleau-Ponty, p. 149.

[12] W.H. Auden, Sonnets from China XIV, *W.H.Auden: Collected Poems*, ed. E. Mendelson (London: Faber & Faber, 1976), p. 154.

[13] Merleau-Ponty, p. 126.

[14] Margaret Hunsberger, The Encounter Between Reader and Text, (Doctoral Dissertation, University of Alberta, 1983), p. 271.

[15] Merleau-Ponty, p. 118.

[16] Merleau-Ponty, p. 147.

[17] See Gadamer, p. 60.

[18] Gadamer, p. 338.

[19] See Michael Polanyi, *The Tacit Dimension*, (New York: Doubleday, 1951).

[20] Cited in Palmer, *Hermeneutics: Interpretation Theory in Schleiermacher, Dilthey, Heidegger and Gadamer*, (Evanston: Northwestern University Press, 1969), p. 133.

[21] Cited in Gabriel Marcel, *Homo Viator: Introduction to a Metaphysics of Hope*, (Chicago: Henry Regnery Co., 1951), p. 28.

[22] See Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, trans. A.Lingis (Pittsburgh: Duquesne University Press, 1969), for example, see p. 61.

[23] Merleau-Ponty, p. 144.

[24] Merleau-Ponty, p. 155.

[25] Palmer, p. 186.

[26] See Levinas, 1969.

[27] David Smith, "Learning to Live in the Home of Language: Hearing the Pedagogic Voice as Poetic," *Phenomenology + Pedagogy, 1*, 1 (1983), 32.

Chapter III

THE GOOD OF UNDERSTANDING

How Can We Dialogue With Illness?

Through "the searching, the trying, the attempting," Blum has shown theorizing to be a way of asking, "How can we understand?" Blum puts into question the nature and purpose of theorizing.

> Is there any difference between theorizing in order to produce a collective, that is, to justify theory because it leads to the production of a collective, and theorizing as the search for the collective that it presupposes (that makes possible theorizing itself)?[1]

We search *for* the meaning of theorizing by searching *through* the meaning of theorizing. We pause before the word as before a monument. Yet, the word abides in us, not as a relic but as a possibility for us from ancient Greek times. What persists in the word is our quest for what is good in human relations. We not only speak about theorizing: we theorize. We become the horizon of the word.

The theorist who sets out to produce a collective has a vision of the common good as the agreement which uniformity manifests. Therefore, the theorist is loyal to the standards established by the existing collective as the resource for the research question and method. A central research concern is "How can agreement be achieved in a problematic situation (a situation of difference)?" A problem is reconcilable through method, the construction of an "ideal type" of an actor, that is, the theorist's re-presentation of his or her rational response in the problematic situation. Through the creation of an "ideal type" of an actor, the theorist "assimilates what is good to words."[2] What is good is a program for action which converts members of the collective into actors who approximate the ideal type in the problematic situation. Through their action the theorist's speech is converted into an "object of common experience,"[3] as each new situation is reduced to a variation of the same situation. The theorist's work is valued according to the efficiency of the uniform action it sponsors in the problematic situation.

"Theorizing as the search for the collective that it presupposes" searches for the good as the agreement which unity manifests. The good is that which speaks in every utterance, every gesture (even by absence) but cannot itself be spoken. The good is therefore the reference for speaking. The theorist unites the members of the collective in the quest for their "deep unity,"[4] the concerted questioning of what is agreed upon but un-thought, what is secure in its everydayness. The theorist's central question is not, "How can we achieve sameness in a situation that highlights difference?" but "How can we re-cognize difference in a situation that is taken for granted?" The theorist is committed to his or her difference from each reader as the origin-al purpose for speaking, the need for dialogue. The theorist's method, then, is not to reconcile difference through an ideal type of an actor but to evoke the uniqueness of each individual's experience in a situation held in common. The task of the theorist is to transform anecdotes into examples which are "personifications of the occasion of thinking."[5] Only in a situation that is critical for the theorist can such examples "come to light."[6] The deep unity of community is evoked in the sharing of such examples of experience which are not mine but like mine, the understanding, "Yes, life is like that. I, too, have lived." However, theorizing does not end in reverie. Theorizing renews itself in thought-ful action, the commitment, "I, too, will live."

Parsons' Theorizing: Professional Health Care

For nearly five decades, human science researchers have seen the experience of illness through the theory of Talcott Parsons, who used the case of illness as an example for the functional analysis of social systems. According to Parsons,[7] care of the ill is a social role relationship aimed at returning a disfunctional individual to a functioning state. The patient is, in a sense, a socially deviant individual, unable to fulfill his or her customary role in society because of illness. The doctor is the professional whose technical qualifications grant him or her the power to return the patient to a functional state. Therefore, the presence of an individual in a doctor's office or emergency ward signifies the inability of the individual to help himself or

herself. The individual who chooses in this way to be a patient grants parental-like authority to the doctor to legitimate the suspicion of illness and to prescribe diagnostic and treatment procedures. The patient's being as a child derives not only from the doctor's technical power to cure but also from the physical and emotional onslaught of illness—the patient wants to be cared for.

The patient assumes a socially and emotionally dependent role. The doctor, however, maintains a professional attitude which is characterized by three attributes. ***Affective neutrality*** is the requirement that the doctor distance himself or herself from the patient; the doctor sympathizes with the patient but does not emphathize with him or her. ***Universalism*** is the requirement that the doctor treat all patients equally regardless of available non-medical information. ***Functional specificity*** is the requirement that the doctor's sphere of influence be bounded by strictly medical concerns as contrasted with spiritual, financial or political concerns which are the arena of other social agencies. Thus, Parsons' model of the ideal type of the doctor-patient relationship entails a basic mutuality, a meshing of expectations. The doctor is trained and expected to act; the patient acknowledges the doctor's expertise and obeys the doctor's orders.

Critiques of Parsons' Theory

The degree of patient involvement is often greater or less than Parsons' ideal type, according to Szaz and Hollender, [1] who identify three types of patient involvement based on behavioral implications of organic symptoms. The norm identified by Parsons is termed ***guidance-cooperation***: the doctor guides, the patient cooperates. Less patient involvement is typified as ***activity-passivity***: the doctor acts upon the patient's passive body. An example is surgery. Szaz and Hollender compare the relationship between doctor and patient to that between parent and infant. Greater patient involvement is typified as ***mutual participation***: the doctor and patient share responsibility. This model is exemplified by people on dialysis and diabetics who care for their health day by day. Szaz and Hollender compare the relationship to

that between adults where one adult has specialized information that the other needs.

Whereas Parsons and Szaz and Hollender rely on a theory of psychologically internalized expectations for a functional model of doctor-patient relationships, Freidson' theorizes that the structure of interpersonal networks that operates in everyday life is the most important variable in the experience of illness. The patient, a member of the lay health system, consults with relatives, persons with similar complaints, the drug store clerk, books,for example; as well as with the doctor, the representative of the professional health system. Any of these consultants can be a source of diagnosis, treatment, and referrals.

Freidson critiques Parsons for seeing the doctor-patient relationship from the doctor's perspective only and for limiting the analysis of the experience of illness to functional expectations only, thus artificially minimizing the possibility of conflict. The doctor "expects patients to accept what he recommends on his terms; patients seek services on their own terms. In that each seek to gain their own terms, there is conflict." [10]

Within the same frame of reference, Freidson critiques the typology of Szaz and Hollender because it represents a continuum of patient involvement without identifying a similar continuum of doctor involvement. Freidson suggests two other types of doctor-patient relationships which are a logical extension of the continuum: ***patient guides—doctor cooperates; patient is active—doctor is passive***. He contends that these two types should not be ignored just because doctors generally reject the possibility of their appropriateness.

Freidson's shift from the analysis of a dyadic relationship to the analysis of conflicting social systems pivots on the critique of expertise (Parsons' category—Functional Specificity):

> neither expertise nor the expert who practises it has been examined carefully enough to allow intelligent and self-conscious formulation of the proper role of the expert in free society. Indeed... expertise is more and more in danger of being used as a mask of privilege and power rather than, as it claims, as a mode of advancing public interest.[11]

Joining in this shift are sociologists such as Berger and Luckman, who describe the institution of medicine as "a sub-universe of meaning" that is, a closed system. An "entire legitimating machinery is at work so that laymen will *remain* laymen, and doctors doctors, and (if at all

possible) that both will do so happily."[12] Illich provides similar commentary.

> Neither high income nor long training nor delicate tasks nor social standing is the mark of the professional, but it is his power to determine what shall be needed by his client. The physician, for instance, became a *doctor* when he left commerce in medicine to the pharmacist and kept prescription for himself.[13]

The discussion of social conflict and legitimating processes loses sight of the person who *is* a doctor and the person who *is* a patient. Faceless laypersons confront faceless experts.

Two Revolutionary Experiments

Cousins shows the face of the experience of illness in his book, *Anatomy of an Illness*, which describes his convalescence from a crippling disease.[14] In 1964, an expert diagnosed the disease as progressive paralysis. Cousins decided to fight the unbeatable disease by involving himself in research and treatment. His doctor cooperated with his suggestions for treatment because alternatives provided by medical science were also unproven and because he was a close friend of Cousins' family. Cousins believed that negative emotions have detrimental effects on health so he planned to cultivate the positive emotions. First, though, he discontinued using pain killers which left toxic wastes in his body producing side effects such as hives, and reducing his body's ability to fight the disease. When the pain became intense, he watched *Candid Camera* and *Marx Brothers* movies. The laughter produced an anaesthetic effect and he was able to sleep for as long as two hours. In 1974, Cousins met the expert who told him he had progressive paralysis. The expert was anxious to know about Cousins' remarkable recovery.

> It all began, I said, when I decided that some experts don't really know enough to make a pronouncement of doom on a human being. And I said I hoped they would be careful about what they said to others; they might be believed and that could be the beginning of the end. [15]

Doctor Robert Mendelsohn, chairman of the Medical Licensing Committee for Illinois and associate professor of preventative medicine and community health in the School of Medicine, University of Illinois, advocates "new medicine" where faith of laypersons in experts is substituted by faith of all in life. [16] New medicine is an ethical system made viable through

family and community. Doctor Mendelsohn theorizes that the "determinants of health" are "life, love, and courage."[17] Believing in life and supported by the love of family and community, the individual finds courage to be responsible for his or her own health. The "new doctor" is a "lifeguard" who "acknowledges nature as the prime healer." [18] The new medical school will have Departments of Ethics and Justice as well as a Department of Iatrogenic Disease. The dominant ethic in the education and practise of the doctor is regard for the rights and dignity of each human being.

Where Does "Theorizing in Order to Produce a Collective" Lead?

Parsons' theory collects doctors and patients in a functional relationship. Inasmuch as a functional relationship is not sufficient for the everyday life of illness, Parsons' theory turns us to the *logos* of the experience of illness. Because of the turning, Heidegger names the "danger" of technology, that is, function as the only criterion for relationship, the "saving power." [19]

Turning from the experience of medical care guided by Parsons' theory, Cousins and Doctor Mendelsohn seek the *logos* of the experience of illness in responsibility—responsibility for oneself and for the other. Cousins finds that assuming responsibility for his own health care with the support of his family and family doctor activates the body's healing mechanisms. His responsibility is tied to his attitude to learn all he can about his illness and possible remedies, and to obey biological and emotional laws governing health. Doctor Mendelsohn advocates that professional medical care be a support system that pivots around the health needs of the family. The responsibility of family members for each other's health includes such essential concerns as nutrition and dedicating time for family activities; in short, putting family first.

This fundamental responsibility of the individual in community reminds us of the dedication of the ancient Greeks to *logos*. More recently, Levinas has analyzed responsibility as a prima facie accountability of the individual for the well-being of his or her neighbor. In a sense, the individual becomes interchangeable with anyone, yet precisely because he or she is unique, this interchangeability is not *like* another but *for* another. This responsibility *for*

another is not bound to personal interest or any pre-established system. It is a subjection to the good which manifests itself in "the unforeseeable response of the chosen one." [20]

Who is the chosen one? And what is the nature of his or her calling? Is the medical doctor truly an expert with the power to cure or a "lifeguard" who "acknowledges nature as the prime healer?" Is the patient dependent on the doctor or responsible for his or her own care? Is the family an emotional backwater or the fulcrum of existence? Are these theories mutually exclusive? In many ways, modern medical care images Parsons' theory. How can we image what belongs to *logos*, the origin of community?

Heidegger's Theorizing: The Homecoming Journey

The theorist's journey has been an allegory for the search for *logos*, the origin of community, since ancient Greek times. The departure of the ancient Greek theorist for the religious festival in a distant town was celebrated by his home community in joyous anticipation of the message he would bring from the gods at his homecoming. "Probably the earliest use of the word *theoros* strongly evoked the components of *theo* and *eros*," Jager writes, "to read approximately 'he who regards and observes (the will of) God.'"[21]

Where shall we go to regard and observe the will of God? Shall we journey to Mount Olympus to view the temple ruins? And what message shall we bring back? Is there any-thing left to say? POLAROID shows us the value of temple ruins. Just as an INSTAMATIC photograph of temple ruins is framed by many tourists as a resource for 'travel talk' without a vision of the temple, so we are "enframed"[22] in a narrow perspective on life: we take for granted that any-thing is a resource only; we do not think to question the essence of the thing.

A journey requires a home base—a place of departure, a place to return to. The ancient Greek theorist knew the soil of that place, his home, his dwelling place. We have no place for rootedness, for learning to know the soil of our existence. The temple ruins are as close as an enframed photograph but family and friends are distant.[23] "Meaning grows out of loyalty to origins. All journeying and every detail of an itinerary must refer to the sphere of dwelling. A

journey cut off from its source degenerates into eternal departure."[24]

Heidegger calls the journey that is eternal departure "*Verfall*"[25] a falling away from our self. Such a journey is marked by "collective indiscrimination" and inauthentic speech. "Everyone is the other and no one is himself. ... The being that *is* us is eroded into commonality; it subsides to a 'oneness' within and among a collective public, herd-like 'theyness.'"[26] Responsibility is relegated to 'them.' Everyone is guided by the values of 'them.' We live in fear of what 'they' prescribe for us. We search for novelty to make life worthwhile. We have become resource-ful overseers of the human resource.

Marcel describes the same situation as a "devitalization process" where the collectivization of individuals results in the "reduction of a personality to an official identity... What is going to become of this inner life?" he asks. "What does a creature who is thus pushed about from pillar to post, ticketed, docketed, labelled, become, for himself and in himself?"[27] And how does an "official identity" speak? When speech has lost its relationship with the essence of what is spoken about, speech deteriorates to chatter, idle talk, ambiguity.

Yet, *Verfall* is an essential part of being in the world, according to Heidegger: being in the world necessitates being with others. *Verfall*, which is not a genuine being with others (because we are not genuine) generates a deep longing for something more. Experiencing what is inauthentic, we dare to hope for what is authentic.

> Desire and hope are the reaching-forward of care. Thus care underlies and necessitates 'the possibility of being free' [authentic]. The careless man and the uncaring are not free. It is care that makes human existence meaningful, that makes a man's life signify.[28]

Logos calls us to care for *logos*. "Travelling in the direction that is a way toward that which is worthy of questioning is not adventure but homecoming."[29] Heidegger identifies three rubrics of authenticity which guide us on our homecoming journey. Wonder at ***what is*** is contrasted with desire for novelty. Speech in the light of *logos* is contrasted with chatter, idle talk, ambiguity. A profound sense of death that wakes us up to life ("Being-towards-death") is contrasted with fear of others.

Chapter IV explores the pathway of wonder at *what is*, speech in the light of *logos*, and "being-towards-death" which leads to an analysis of Kierkegaard's question and method for understanding faith as an example of an appropriate question and method for this research, "How can we understand the life of illness?"

Notes

[1] Alan Blum, "Theorizing," *Understanding Everyday Life*, ed. J.Douglas, (Chicago: Aldine, 1970), p. 308.

[2] Alan Blum, *Theorizing*, (London: Heinemann Educational Books, 1974), p. 20.

[3] Blum, *Theorizing*, p. 132.

[4] Blum, *Theorizing*, p. 34.

[5] Blum, *Theorizing*, p. 74.

[6] Blum, *Theorizing*, p. 77.

[7] Talcott Parsons, *The Social System*, (New York: The Free Press, 1951).

[8] Cited in S.Bloom, *The Doctor and His Patient: A Sociological Interpretation*, (New York: Russell Sage Foundation, 1963).

[9] E.Freidson, "Client Control and Medical Practice," *American Journal of Sociology*, 65, (1960), 374-382.

[10] Cited in H.Freeman, S.Levine, & L.Reeder, eds., *Handbook of Medical Sociology*, (Englewood Cliffs, N.J.: Prentice-Hall, 1972), p. 326.

[11] Freidson, 160, p. 374.

[12] P.Berger & T.Luckman, *The Social Construction of Reality*, (New York: Penguin Books, 1966). p. 102; see also p. 105.

[13] Ivan Illich, "Disabling Professions: Notes for a Lecture,"*Contemporary Crises*, (1977), 361.

[14] Norman Cousins, *Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration*, (New York: W.W.Norton, 1979), p. 160.

[15] Cousins, p. 160.

[16] R. Mendelsohn, *Confessions of a Medical Heretic*, (New York: Warner Books, 1979), p. 255.

[17] Mendelsohn, p. 260.

[18] Mendelsohn, p. 260; see also p. 281.

[19] See Martin Heidegger, "The Question Concerning Technology" and "The Turning," *The Question Concerning Technology and Other Essays*, (New York: Harper & Row, 1977), for example, pp. 28, 42.

[20] Emmanuel Levinas, *Otherwise Than Being or Beyond Essence*, trans. A.Lingis (Boston: Nijhoff, 1981), p. 145.

[21] B.Jager, "Theorizing, Journeying, Dwelling," *Phenomenological Psychology*, 2 (1975), 235.

[22] See Heidegger, 1977.

[23] See J.H.van den Berg, *The Changing Nature of Man*, (New York: Dell, 1975).

[24] Jager, p. 253.

[25] See M.Heidegger, *Being and Time*, (New York: Harper & Row, 1962), for example, pp. 42, 219-224.

[26] George Steiner, *Heidegger*, (Glasgow: William Collins Sons & Co., 1978), p. 90.

[27] Gabriel Marcel, *The Mystery of Being* (Vol.1), (London: Harvard Press, 1950), p. 27; see also p. 29.

[28] Steiner, p. 98.

[29] Heidegger, *The Question Concerning Technology and Other Essays*, p. 180.

Chapter IV

THE HOW OF UNDERSTANDING

There is a way of thinking, in contact with the event, which seeks its concrete structure[1]

Wonder at What Is: The Essence of Truth

We observe the difference between a diamond stone and a glass stone that are identically cut and mounted. The diamond is truly a diamond, the glass is truly not a diamond, though it may appear so. Each stone has the possibility of a genuine appraisal (its own) and the possibility of a false appraisal (if one is taken for the other). When the stone is, in fact, a diamond, and we say, "This stone is a diamond," we have expressed a true proposition. The truth (correctness) of the proposition is found in the truth (correctness) of the matter. The proposition presents the matter, the proposition *lets* "the thing stand opposed as object."[2] But what is the meaning of 'let' whereby the proposition "subordinates itself to the directive that it speaks of beings *such-as* they are"?[3]

'Let' provides an opening for the shining of the essence of the diamond: the proposition, 'This stone is a diamond' lets be "what something is, as it is."[4] 'Let' is the ground of the possibility of correctness. 'Let' is the freedom of the object to be what it is. "The essence of truth is freedom."[5]

The Greek word for the shimmering freedom of the essence of an object is *alêtheia*, usually translated 'truth,' although more literally, "unconcealment."[6] "Unconcealment" helps us think beyond truth as correctness to the ground of correctness, freedom, an enabling of unconcealment. We are the place where all beings are unconcealed. We are possessed by the freedom of the object to disclose itself. Therefore, our manner towards all beings is openness: we live in the question. History ever begins with the question.

Our manner of being among beings is openness. The manner of being of all other beings is unconcealment. Why, then, has our relationship to beings through history not become fixed

in absolute knowledge? To consider this question, we must search the other side of openness and the other side of unconcealment: Heidegger names the other side of openness, "errancy"; the other side of unconcealment, "concealment."[7] 'Errancy' is our predisposition to satisfy our wants and needs as easily as possible, to ask superficial questions because everything is already familiar. Errancy closes us off from the unconcealing of beings: when we are a closed place, the essence of beings is sheltered in concealment. We are always the place of an opening-closing. And the unconcealing of beings is always sheltered in concealing. Thus, the mystery of being is preserved from us and for us.

Heidegger proposes that "the essence of truth is the truth of essence."[8] "The essence of truth" means "accordance between knowledge and beings" (correctness). "The truth of essence" means "sheltering that lightens" (*alêtheia*). 'Is' means "lets essentially unfold" (freedom). The origin of wonder at *what is*, is freedom, the questioning openness of letting-be what is disclosing itself.

Just as a life of openness to the object cannot be demanded, so a life of openness to the other cannot be demanded. "How could a life of dialogue be demanded?" Buber writes. "There is no ordering of dialogue. It is not that you *are* to answer but that you *are able*."[9] How can we respond to the appeal, "You are able?" How can we be an open place?

Speech in the Light of Logos: The Work of Art

The artist is an open place for the unconcealing-concealing of being. Truth happens in the work of art, the artist's place, the place where unconcealing and concealing strive.[10] Heidegger gives the example of Van Gogh's painting of peasant shoes. The shoes stand no-where, any-where, yet never on the canvas. The canvas disappears, not under the paint, but with the paint, with the artist, concealed in the unconcealing of the shoes. For, in the work of art, the shoes re-present the world of the peasant woman.

> From the dark opening of the worn insides of the shoes the toilsome tread of the worker stares forth. In the stiffly rugged heaviness of the shoes there is the accumulated tenacity of her slow trudge through the far-spreading and ever-uniform furrows of the field swept by a raw wind. On the leather lie the dampness and richness

> of the soil. Under the shoes slides the loneliness of the fieldpath as evening falls. In the shoes vibrates the silent call of the earth...[11]

In the work of art, the shoes that the peasant woman wears without thinking about it bring forth a world that we recognize, a world we assumed we did not know. How does the truth of the peasant woman's world come into play in Van Gogh's painting and in Heidegger's writing?

The phrase, 'come into play,' signifies that play is a clue to the origin of the work of art. Play detaches us from everything, then gives us back the whole of our being.[12] For example, the world of play envelops the child who plays house: the child disappears into an adult identity. The inner consistency of the world of play constrains everyone who enters its threshold to obey the rules of play. Willing parents pretend they are neighbors who 'visit' the child for a cup of tea. The play takes place for the child as well as in the child. To say that the child is pretending to be an adult misses the significance of the child's re-presentation of what it means to the child to be an adult. Parents recognize themselves in the child's play and return to the everyday world a bit wiser for the experience.

"Human play finds its true perfection in being art."[13] Just as the playing child is set apart in a closed world—a world with its own compelling structure—so the work of art is a closed world. The two complementary aspects of the structure of this closed world founds the permanence of the work of art in its temporality: the work of art is a meaningful whole which can be repeatedly re-presented; only in each re-presentation of the work of art can the meaningful whole be unconcealed. Like a tree through the seasons and the years, the work of art retains its identity in the changing aspects of itself. "It has its being only in becoming and return."[14]

The artist is the open place for the becoming of the work of art. But, like the playing child, the artist disappears in the play of the work of art. Unlike the playing child, this disappearance is not just for himself or herself but for everyone. The disappearance of the artist for everyone is the perfection of play: it enables the spectator to be the open place for the return of the play of the work of art.

Like the Greek theorist at the religious festival, the spectator fulfills the purpose of the work of art by being there. "Theoria is a true sharing," Gadamer writes, "being totally involved in and carried away by what one sees."[15] Participation in the world of the work of art estranges the spectator from the taken-for-grantedness of the everyday world. "What existed previously no longer exists," Gadamer writes. "But also that what now exists, what represents itself in the play of art is what is lasting and true."[16] For example, Van Gogh's painting of peasant shoes fills the spectator with the spirit of the peasant woman's world; Heidegger's writing analyzes the experience of the spectator who sees the peasant shoes as for the first time in the work of art. Severed from their common ground, the peasant shoes are grounded in their essence, their equipmental reliability.[17] The spectator/theorist leaves home (what is familiar) to come home (to what is authentic).

Like the child whose play at being an adult 'speaks' to the parents, the play of the work of art 'speaks' to the spectator. The "joy of recognition," Gadamer writes, is that "more becomes known that is already known. In recognition what we know emerges, as if through an illumination...".[18]

The illumination is the shimmering freedom of the subject matter to be what it is in the play of the work of art. How can the human science researcher be the place of an opening for such illumination? In other words, how can spectator/theorist be artist and vice versa? 'Spectator/Theorist be artist' means: to re-search the temporal for what is "lasting and true" in a way that transforms what is lasting and true "into an image or a form."[19] For example, we *see* Mona Lisa's smile, we *hear* Bach's chorales, and we *read* Kierkegaard's description of Abraham's journey of faith. 'Artist be spectator/theorist' means: to return to the community (as the ancient Greek theorist returned from the religious festival) to speak the life of one who lives the truth of the subject matter. This translation of the unique experience into the life we can share is expressed through the theme. The dwelling place of thematic research is the question, "What belongs to *logos*, the origin of community, the origin of our relationship to each other?" Kierkegaard shows us how spectator/theorist can be artist and vice versa, how

"being-towards-death" can re-search life.

Being-Towards-Death Researches Life: Kierkegaard's Question and Method

In *Fear and Trembling,*[20] a phenomenology of faith, Kierkegaard the spectator/theorist is artist. Kierkegaard leaves the common ground of the everyday experience of faith. For example, we agree that we live by faith. We do not need to say,"We believe that the chairs we sit on will support us. We believe that the weigh scales are accurate. We believe..." We make faith appear incidental to the taken-for-grantedness of everyday life. Such faith needs no father to care for it. Yet Abraham was the father of faith.

Kierkegaard journeys to the estranged ground of the literary work of art, the Biblical account of the faith of Abraham. He fulfills the work of art by being there. "Finally, he forgot everything else because of it; his soul had but one wish, to see Abraham, but one longing, to have witnessed that event."[21] "Occupied" by the "shudder of an idea,"[22] Kierkegaard becomes the open place of a question: Who can understand Abraham?

> And God did tempt [test] Abraham... And He said, Take now thy son, thine only son Isaac, whom thou lovest, and get thee into the land of Moriah; and offer him there for a burnt offering upon one of the mountains which I will tell thee of.
>
> And Abraham rose up early in the morning, and saddled his ass, and took two of his young men with him, and Isaac his son, and clave the wood for the burnt offering, and rose up, and went unto the place of which God had told him.
>
> Then on the third day Abraham lifted up his eyes, and saw the place afar off...
>
> And Isaac spake unto Abraham his father, and said, My father: and he said, Here am I, my son. And he said, Behold the fire and the wood: but where is the lamb for a burnt offering?
>
> And Abraham said, My son, God will provide himself a lamb for a burnt offering: so they went both of them together.
>
> And they came to the place which God had told him of; and Abraham built an altar there, and laid the wood in order, and bound Isaac his son, and laid him on the altar upon the wood.
>
> And Abraham stretched forth his hand, and took the knife to slay his son.
>
> And the angel of the Lord called unto him out of heaven, and said, Abraham, Abraham: and he said, Here am I.

> And he said, Lay not thine hand upon the lad, neither do thou any thing unto him: for now I know that thou fearest God, seeing thou hast not withheld thy son, thine only son, from me.
>
> And Abraham lifted up his eyes, and looked, and beheld behind him a ram caught in a thicket by his horns, and Abraham went and took the ram, and offered him up for a burnt offering in the stead of his son.[23]

Responding to this text, Kierkegaard is artist. In *Fear and Trembling*, the relationship between God and Abraham strives for unconcealment in Kierkegaard's stories of how Abraham could have lived the experience with Isaac, how a mother could live the experience of weaning with her child.[24] In love, the mother withholds her warmth and sustenance from the child at the right time. And the child lives on by faith in the mother, for who else is the source of sustenance?

Abraham lived by faith, sojourning in a foreign land, daily bereft of the companionship and language of his kin. His homeland was the promise of God. Abraham grew old waiting for the fulfillment of the promise, the birth of his only son, Isaac, through whom his descendants would be named inheritors of the promised land. And each time Abraham looked on Isaac his son, he saw God his father. How could Abraham ever be weaned from one without losing all?

Love transforms Abraham's ordeal from murder into tragedy; faith transforms it from tragedy into a "holy and God-pleasing act, a paradox that gives Isaac back to Abraham again."[25] Kierkegaard the artist is spectator/theorist as he researches three themes of faith that have come to light in his response to the Biblical text.

1. "Is There a Teleological Suspension of the Ethical?"[26] "In ethical terms, Abraham's relation to Isaac is quite simply this: the father shall love the son more than himself."[27] If Abraham had sacrificed himself, all human beings would understand the selfless act, for he was the father of Isaac—he loved his son more than himself. If Abraham had turned back at any time during the ordeal, all human beings would understand the rational act, for he was the father of Isaac—he loved the son whom he had seen more than God whom he had not seen. More

deeply, how could Abraham love Isaac less by loving God more? Yet who can understand Abraham? He was the father of faith—he was willing to lose all, and, at every moment, he believed he would receive all back again.

2. "Is There an Absolute Duty to God?"[28] The tragic hero (for example, Terry Fox), relinquishes one (himself) for the sake of the ethical (universal). Abraham relinquishes the ethical for the sake of one. "For God's sake and—the two are wholly identical—for his own sake. He does it for God's sake because God demands this proof of his faith; he does it for his own sake so that he can prove it."[29] The tragic hero's relationship to the absolute is determined by his relationship to the ethical, his duty to man. Abraham's relationship to the ethical is determined by his relationship to the absolute, his duty to God. "The paradox of faith, then, is this," Kierkegaard writes, "that the single individual is higher than the universal."[30]

3. "Was it Ethically Defensible for Abraham to Conceal His Understanding from Sarah, Eliezer, and from Isaac?"[31] The tragic hero speaks a universal language. Abraham speaks "in tongues."[32] He speaks the truth that conceals the truth from Isaac, his son. He keeps silence with Sarah, his wife, and Eliezer, his servant. Kierkegaard writes that he longed to "go along on the three day journey when Abraham rode with sorrow before him and Isaac beside him."[33] For he recognized the sorrow of silence—the sorrow of the individual without community. Abraham is cut off from all for the sake of the One who justifies him. Yet, at every moment, faith transforms the ordeal into personal victory. Who can understand Abraham?

The question, "Who can understand Abraham?" is permeated by the question, "How ought we to live?" This question is given to us as a possibility for living in faith. There is nothing in the world that we can see or touch that has the name, faith. When we speak of faith, we name a manner of openness, a way of living in the question. We name a man, Abraham. Research in the human sciences begins with the name of a human being, the re-collection of a life. This life is, in some sense, not only one life but our life; it is our ordeal, our possibility.

For many of us, Abraham had long ago ceased to be a man on a journey to obey God. He was already the patriarch and there were no questions in us. But Kierkegaard begins where the Biblical work of art begins, with one moment in the life of a man. Thus, Kierkegaard's re-search mediates between the work of art and our forgetfulness of the beginning.

Beginning with one life, Kierkegaard *is* ("lets essentially unfold")[34] the open place for the concealing-unconcealing of the beginning: faith. Faith is free to be what it is in Kierkegaard's response to Abraham's life, a new work of art. Kierkegaard, a human being like Abraham, is put into question by the themes of faith that 'speak' through this work of art. Now spectator/theorist, he dialogues with these themes. Our understanding of faith deepens. At the same time, our awe increases. So Kierkegaard's writing is not the last word but an other word, a word that finds its fulfillment in us. Forever, Abraham begins his homecoming journey.

Who can understand Abraham? Kierkegaard's way of researching this question, a question that comes to life in each of our lives, is the way of the spectator/theorist, the way of the artist; a way to understanding. How can we understand the life of illness?

Methodological Procedures for Researching the Life of Illness

We ask, "How can we understand the life of illness?" More deeply, we wonder, "How ought we to live?" And more incessantly, we ponder, "Why illness?" In the first four chapters, we have journeyed through the research question in an effort to learn how to articulate this question of the heart. The pathway intersected and paralleled the paths of many who have gone before. The creative work of laying down this path responds to their creative work. For example, Karatheodoris opened up the possibilities of the dialectic, "All is one," for us. Gadamer kept the possibilities open and showed us how pain enables us to live in the question. Blum's re-search through theorizing led us to the pathway described by Heidegger as the homecoming journey. With Kierkegaard's help, we witnessed the homecoming journey in the Biblical account of the life of Abraham. And with van Manen's help, we take up the journey as

research for living. [35] We want to understand the homecoming journey by means of illness in the lives of family, friends, and medical professionals by reading literary works of art as sources for hermeneutical phenomenological research.

Dialogue for this research begins when I read literary works of art describing the experience of illness. The subject matter of each literary work of art shines through its situatedness in a historical context and 'speaks' into our context in a way that transcends our context, too. At the same time, the concealing-revealing of the subject matter binds the unknown author to us in a context of giving. "The sharing of meaning with integrity is the generous gift of the creative writer. Our own experience is reconfirmed and clarified, as well as extended."[36] In response, we too, are willing to "share meaning with integrity." Life speaks to life and we respond, not with a "bald re-enactment," but with a "new creation of understanding." [37]

During the reading of each literary work of art, I excerpt paragraphs (verses, entries, etc.) which 'speak' eloquently the experience of illness in a way that is typical of that particular work of art. These excerpts I respond to freely, in the manner of unarticulated conversation with the text. This reading-reflection leads to conversation with a doctor, chaplain, nurse, and mother, each of whom I ask to read excerpts from a literary source which is particularly relevant to his or her experience of illness, and share "descriptive examples of the lived through quality"[38] of illness. The dialogic procedure here takes on the form of interviewing (L. *inter*, "between"; *videre*, "seeing"),[39] that is, "seeing between" the personal readings and reflections, the one teacher, *logos*. The renewal of dialogical conversations invites the solitary task of hermeneutic writing, a diligent search for the *logos* of the narrative and descriptive language found in the literary sources, interview notes and transcripts, and related research.[40] Reading and re-reading continues to be a major enabler of the search to understand the experience of illness during writing. Etymological sources provide clues to the richness of meaning in words which have become so sedimented in routine expression that we don't hear all they say.[41] Idioms are also explored for the meanings buried in their familiar usage.[42] The research

becomes the between.

Using all the sources of research, I search for themes of the life of illness. The first section of each chapter is the written search. The title of each chapter is the major theme, a theme of *logos*; minor themes which relate to the major theme are identified by side-headings, marginal notes, and essay style responses. This "First Reflection" provides a way of thinking about illness which yields thematic statements that remain open to living thought. The second section of each chapter, "Second Reflection," identifies these thematic statements and searches through them in a questioning way.[43] Thematic statements attest to the unity of our experience while evoking the uniqueness of individual experience in a way that opens us up to new experience.[44]

The research begins with Chapter V which concerns the life of illness as experienced by Ivan Ilyitch in Tolstoy's *The Death of Ivan Ilyitch*. In **One Against the Other Searches for the Other**, I search with the help of a chaplain through Ivan's experience of *letting go of the things* of life to find the meaning of life. The source for Chapter VI, **One With the Other**, is the diary of Pauline Erickson, a young woman suffering from heart failure due to lung disease. Pauline experienced illness as the *struggle to be born into a life of illness*, to learn to be willing to die when she loved life so much. In Chapter VII, **One For the Other**, I search, with the help of a doctor, through the experience of a doctor during the outbreak of the plague in Camus' novel, *The Plague*. What does the doctor do when there is no technology to sustain life? This question opens to *the heart of pity* in medical care. In Chapter VIII, **One By the Other**, I search, with the help of a nurse, through the experience of nursing in Florence Nightingale's writings. What is it like *to be there a nurse* during illness? In Chapter IX, **One Without the Other**, I search, with the help of my mother, through the experience of family and friends as they *journey through grief*. Tennyson's poem, "In Memoriam, A.H.H." is the source of dialogue concerning the daily life of illness, death, and grief. The research dialogue continues with re-reading and reading other sources, reflecting, interviewing, and writing. In Chapter X, **The Gathering**, I gather the way of research to the content of research through my experience as a *student of the*

research question. This final chapter ends with my description of what *the homecoming* through illness means to me, a new beginning for each day.

What is the research journey to understand illness like?

1. Lived Experience Questions Us.

> *Recollection of 1971.* I was waiting in the dimly-lit hall of the dialysis unit. I saw Jim[45] leaning against the wall, gasping for air. He was hunch-backed and barrel-chested with bone disease. I could see the pain vibrating in him, burning him up. And darkly, the fatigue encircled his eyes. Staring at him, I feared my pain.
>
> Then he smiled at me. And in his eyes, I saw how strong this suffering man; how strong his kindness towards me, how strong his dignity. I believed if he could live, so could I. I came away from the encounter with new courage.

2. Illumination of Experience by a Literary Work of Art.

The learning I lived in that encounter was wordless until I read *Man's Search for Meaning* by Victor Frankl a decade later. Frankl writes that suffering requires a choice between futures—hidden futures since it all appears one to the onlooker.

> Everything can be taken from a man but one thing: the last of human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way.[46]

3. Written Description of Lived Experience.

The writing of the experience (1) was evoked by reading the excerpt (2). Dialogue with the text is the action of interpretation. The interpretation is always one possible interpretation.

4. Emergence of a Theme.

As interpreter, I am also witness to the meaning of my interpretation as a way of living in the question. The literary excerpt and my response to it do not encapsulate my learning, closing the matter once and for all. These statements are my question because they question me. There is a mystery here, a miracle:

I knew a man who chose to suffer well.

And there is a community of shared meaning here, a theme:

We can choose to suffer well.

But what is the light by which such a choice comes to life in the life of an individual? What

is this humiliation of the will that enables one to live in humility? What is this "healing process" whereby "one can actually improve even as the body disintegrates?"[47]

5. Return to Lived Experience.

These questions resonating in the theme draw us back into the research question. To be drawn back into the research question is to be impelled forward into life to participate in the mystery and the miracle expressed in the theme. *Interview with Shirley Wood, R.N., September, 1984.* Mike[48] made a deep impression on me. He was a triple amputee on dialysis because of diabetes. He was always cheering *you* up. He did all sorts of marvelous things—he worked with a physiotherapist to develop films to help new amputees, he invited nurses and patients into his home...

Shirley expressed the theme of her encounters with Mike:

We can choose to live to the very fullest of our capabilities, working to discover our full potential.

The major theme, 'We can choose to suffer well,' is made visible as an action by this related theme. What is the essence of this action— Mike's cheerfulness, Jim's smile? Is it not hospitality in the Greek sense? But Mike and Jim were the strangers...

6. Once Again, The Journey.

Once again, we stand at the threshold of the beginning. Once again, we "cast [our] bread upon the waters" in expectation of the promise, "You will find it after many days."[49] Once again, this tension of casting away and finding is expressed in the question and the theme; the theme in the question and the question in the theme, and the journey between.

Notes

[1] Maurice Merleau-Ponty, *Signs*, (Evanston: Northwestern University Press, 1964), p. 363.

[2] Martin Heidegger, "On the Essence of Truth," *Basic Writings*, (New York: Harper & Row, 1977), p. 123. "Wonder at What Is: The Essence of Truth" is based on this essay.

[3] Heidegger, p. 124.

[4] Heidegger, p. 124.

[5] Heidegger, p. 125.

[6] Heidegger, p. 127.

[7] Heidegger, p. 135; see also p. 132.

[8] Heidegger, p. 140.

[9] Martin Buber, *Between Man and Man*, ed. R.G. Smith (London: Collins Clear-Type Press, 1974), p. 54.

[10] Heidegger, "The Origin of the Work of Art," *Basic Writings*, p. 173.

[11] Heidegger, p. 163.

[12] H-G. Gadamer, "The Ontology of the Work of Art and Its Hermeneutical Significance," *Truth and Method*, (New York: Seabury Press, 1975), p. 113. The description of play as a clue to the origin of the work of art is based on this essay.

[13] Gadamer, p. 99.

[14] Gadamer, p. 110.

[15] Gadamer, p. 111.

[16] Gadamer, p. 100.

[17] See Heidegger, p. 163.

[18] Gadamer, p. 102.

[19] Richard Palmer, *Hermeneutics: Interpretation Theory in Schleiermacher, Dilthey, Heidegger and Gadamer*,(Evanston: Northwestern University Press, 1969), p. 169; Ibid.

[20] Søren Kierkegaard, *Fear and Trembling/Repetition*, (Princeton, NJ: Princeton University Press, 1983).

[21] Kierkegaard, p. 9.

[22] Kierkegaard, p. 9.

[23] Gen. 22:1-13.

[24] See Kierkegaard, pp. 10-14.

[25] Kierkegaard, p. 53.

[26] Kierkegaard, p. 54.

[27] Kierkegaard, p. 57.

[28] Kierkegaard, p. 68.

[29] Kierkegaard, p. 60.

[30] Kierkegaard, p. 70.

[31] Kierkegaard, p. 82.

[32] Kierkegaard, p. 114.

[33] Kierkegaard, p. 9.

[34] Heidegger, p. 140.

[35] See Max van Manen, "Practicing Phenomenological Writing," *Phenomenology + Pedagogy*, *2*, 1 (1984), 36-69, for a comprehensive description of phenomenological research writing.

[36] Margaret Hunsberger, *The Encounter Between Reader and Text*, (Doctoral Dissertation, University of Alberta, 1983), p. 272.

[37] David Hoy, *The Critical Circle*, (Berkeley: University of California Press, 1978), p. 49; see also Gadamer, p.430.

[38] Max van Manen, "Doing Phenomenology: Procedural Schema for the Methodology of Questioning in Phenomenological Research Writing," (Edmonton: Faculty of Education Publication Services, 1983).

[39] Ernest Klein, *A Comprehensive Etymological Dictionary of the English Language*, (New York: Elsevier Publishing Co., 1971), p. 384.

[40] Examples of phenomenological research related to illness include: J.H.van den Berg, *Psychology of the Sick Bed*, (Pittsburgh: Duquesne University Press, 1966), a phenomenological description of what it is like to be sick in bed at home or in the hospital; F.J.Buytendijk, *Pain*, (London: Hutchinson, 1961), on the experience of suffering pain; P.-A. Field, "A Phenomenological Look at Giving an Injection," *Journal of Advanced Nursing*, 6 (1981), 291-296, on the nurse's personal and professional responses to the patient's need for an injection.

[41] Note the examples, "Cardiology" and "Hospitality," p. 4; see also "Theorizing," p. 12.

[42] Note the examples, "The sun is setting." "Tomorrow is another day." p. 7.

[43] The exception to this structure of research writing is Chapter IX on the experience of grief. Research writing is described in Chapter X.

[44] See Max van Manen, "Action Research as Theory of the Unique: From Pedagogic Thoughtfulness to Pedagogic Tactfulness," (Paper presented at the American Educational Research Association Conference, New Orleans, 1984).

[45] Jim is a pseudonym.

[46] Victor Frankl, *Man's Search for Meaning: An Introduction to Logotherapy*, (New York: Washington Square Press, 1963), p. 65.

[47] Jurritt Bergsma and David Thomasa, *Health Care: Its Psychological Dimensions*, (Pittsburgh: Duquesne University Press, 1982), p. 171.

[48] Mike is a pseudonym.

[49] Eccles. 11:1,2.

Chapter V

IVAN ILYITCH: ONE AGAINST THE OTHER SEARCHES FOR THE OTHER

First Reflection: On *The Death of Ivan Ilyitch*

In *The Death of Ivan Ilyitch*,[1] Leo Tolstoy portrays Ivan as a husband, father, friend, judge, master, Catholic, poker enthusiast. All of Ivan's pursuits are cast in shadow by the events of his death, a lonely death degraded by the pride of his life, propriety, which sets him against the other even as he desperately searches for the other.

Encounter With Death

Knowing without believing.

What does mortal mean to one who is not suffering death?

Ivan reflects on his life because of his illness.

Life is understood in the fullness of particular experiences.

Feelings and ideas are personal possessions. Why "ought" Ivan die?

> At the bottom of his heart Ivan Ilyitch knew that he was dying; but so far from growing used to this idea, he simply did not grasp it—he was utterly unable to grasp it.
>
> The example of the syllogism that he had learned in Kiseveter's logic—Caius is a man, men are mortal, therefore Caius is mortal—had seemed to him all his life correct only as regards Caius, but not at all as regards himself. In that case it was a question of Caius, a man, an abstract man, and it was perfectly true, but he was not Caius, and was not an abstract man; he had always been a creature quite, quite different from all others; he had been little Vanya with a mamma and papa, and Mitya and Volodya, with playthings and a coachman and a nurse; afterwards with Katenka, with all the joys and griefs and ecstasies of childhood, boyhood, and youth. What did Caius know of the smell of the leathern ball Vanya had been so fond of? Had Caius kissed his mother's hand like that? Caius had not heard the silk rustle of his mother's skirts. He had not made a riot at school over the pudding. Had Caius been in love like that? Could Caius preside over the sittings of the court?
>
> And Caius certainly was mortal, and it was right for him to die; but for me, little Vanya, Ivan Ilyitch, with all my feelings and ideas—for me it's a different matter. And it cannot be that I ought to die. That would be too awful. (pp.43,44)

To whom can we appeal concerning Ivan's life, moments treasured like polished stones, hidden in a box—"the smell of the leathern ball," "the silk rustle of his mother's skirts," "a riot at school over the pudding?" Are these not treasures worth defending? Yet death treats Ivan's life as a common thing: death laughs at Ivan and his jewels. The sentence of death cannot be

appealed. Ivan, like Caius, must die. Ivan knows his death is imminent but he cannot believe it. And he cannot relinquish his jewels, his very own jewels, his very own Vanya.

Against Death

The fear of 'It'

Hiding from 'It'

Compelled by 'It'

Diversions from 'It'

Failure

> *It* came and stood confronting him and looked at him, and he felt turned to stone, and the light died away in his eyes, and he began to ask himself again, 'Can it be that *It* is the only truth?' And his colleagues and his subordinates saw with surprise and distress that he, the brilliant, subtle judge, was losing the thread of his speech, was making blunders. He shook himself, tried to regain his self-control, and got somehow to the end of the sitting, and went home with the painful sense that his judicial labours could not as of old hide from him what he wanted to hide; that he could not by means of his official work escape from *It*. And the worst of it was that *It* drew him to itself not for him to do anything in particular, but simply for him to look at *It* straight in the face, to look at *It* and, doing nothing, suffer unspeakably.
>
> And to save himself from this, Ivan Ilyitch sought amusements, other screens, and these screens he found, and for a little while they did seem to save him; but soon again they were not so much broken down as let the light through, as though *It* pierced through everything, and there was nothing that could shut *It* off. (p. 45)

When is death present? When is it absent? 'It' is always present. Our screen of activities and amusements cannot veil 'It.' "At the origin of diversion, of the will to be diverted or amused at any price, there is an attempt to escape, but from what? It can only be from oneself."[2] This hide-and-seek is played like the children's game: when 'It' catches us in our hiding place, we become 'It.' "Ultimately, we cannot keep up the deception."[3] Death wears our own face.

Against Deception

Try persuasion

> Ivan Ilyitch's great misery was due to the deception that for some reason or other every one kept up with him—that he was simply ill, and not dying, and that he need only keep quiet and follow the doctor's orders, and then some great change for the better would be the result. He knew that whatever they might do, there would be no result except more agonizing sufferings and death.

Try denial

And he was made miserable by this lie, made miserable at their refusing to acknowledge what they all knew and he knew, by persisting in lying over him about his awful position, and in forcing him too to take part in this lie. Lying, lying, this lying carried on over him on the eve of his death, and destined to bring that terrible, solemn act of his death down to the level of all their visits, curtains, sturgeons for dinner... was a horrible agony for Ivan Ilyitch.

Try routinizing illness

And, strange to say, many times when they had been going through the regular performance over him, he had been within a hair's-breadth of screaming at them: 'Cease your lying! You know, and I know, that I'm dying; so do, at least, give over lying!'

The need for honesty

But he had never had the spirit to do this. (p. 50)

The experience of dying is reduced to a parody of diet and rest. Everyone participates in the stage play. We know our parts by heart. With all our heart, each of us does not want to die. With all our heart, each of us faces "the terrible fact" of death alone.[4]

The Struggle for Truth

Who cares?

Apart from this deception, or in consequence of it, what made the greatest misery for Ivan Ilyitch was that no one felt for him as he would have liked them to feel for him. At certain moments, after prolonged suffering, Ivan Ilyitch, ashamed as he would have been to own it, longed more than anything for some one to feel sorry for him, as for a sick child. He longed to be petted, kissed, and wept over, as children are petted and comforted. He knew that he was an important member of the law-courts, that he had a beard turning grey, and that therefore it was impossible. But still he longed for it.

Who comforts?

And in his relations with Gerasim there was something approaching to that. And that was why being with Gerasim was a comfort to him. Ivan Ilyitch longs to weep, longs to be petted and wept over, and then there comes in a colleague, Shebek; and instead of weeping

Who perpetuates the falsity?

and being petted, Ivan Ilyitch puts on his serious, severe, earnest face, and from mere inertia gives his views on the effect of the last decision in the Court of Appeal, and obstinately insists upon them. This falsity around him and within him did more than anything to poison Ivan Ilyitch's last days. (p. 51)

This desperate loneliness is overcome when we share our moments with each other. Just holding a hand is "a conversation of common experience."[5] Yet we continue to engage in the habitual play that we condemn by disengaging our life and death from each other. We retreat from death with proud words and sophisticated manner. And the play goes on.

The Doctor Gives Hope

Medical detail veils the lived-through quality of the struggle against illness.

At half-past eleven the celebrated doctor came. Again came the sounding, and then grave conversation in his presence and in the other room about the kidney and the appendix, and questions and answers, with such an air of significance, that again, instead of the real question of life and death, which was now the only one that confronted him, the question that came uppermost was of the kidney and the appendix, which were doing something not as they ought to do, and were for that reason being attacked by Mihail Danilovitch and the celebrated doctor, and forced to mend their ways.

The patient "listens" to the doctor's manner for a sign of hope.

Pity is a response to hope.

The celebrated doctor took leave of him with a serious, but not a hopeless face. And to the timid question that Ivan Ilyitch addressed to him while he lifted his eyes, shining with terror and hope, up towards him, Was there a chance of recovery? He answered that he could not answer for it, but that there was a chance. The look of hope with which Ivan Ilyitch watched the doctor out was so piteous that, seeing it, Praskovya Fyodorovna positively burst into tears, as she went out of the door to hand the celebrated doctor his fee in the next room. (p. 56)

"The doctor gives a little hope, not very much hope," and Ivan's wife gives the doctor the fee.[6] How much does a little hope cost? A little hope empties Praskovya Fyodornovna's purse. How much does a little hope give? A little hope fills Ivan with gratitude. The presence of someone who is hopeful provides a moment of companionship on the "terribly perilous, trying journey."[7] The doctor cares enough to give a little hope. The wife cares enough to pay the fee, and she responds to Ivan's gratitude with tears. For a moment, Ivan is not alone.

Against God

The tumult of helplessness, loneliness, cruelty,

he could restrain himself no longer, and cried like a child. He cried at his own helplessness, at his awful loneliness, at the cruelty of people, at the cruelty of God, at the absence of God.

punishment,

'Why hast Thou done all this? What brought me to this? Why, why torture me so horribly?'

senselessness,

He did not expect an answer, and wept indeed that there was and could be no answer. The pain grew more acute again, but he did not stir, did not call. He said to himself, 'Come, more then; come, strike me! But what for? What have I done to Thee? What for?

is quelled by silence.

Then he was still, ceased weeping, held his breath, and was all attention; he listened, as it were, not to a voice uttering sounds, but the voice of his soul, to the current of thoughts that rose up within him. (p. 60)

The experience of dying gives us the opportunity to be more fully conscious of life. "We pray, 'Spare us from death with our boots on.'"[1] At this moment in the experience of dying, Ivan is angry at God. The Latin word for anger, *angere*, means "to press together, throttle, torment."[2] Ivan's life is pressed together into this moment of helplessness; he is throttled by the fear of death, and life; he is tormented by his loneliness. Convinced of the absence of God, he seeks the presence of God more earnestly than ever before. Ivan Ilyitch, the fluent judge, stands in the dock. Ivan listens.

Listening to the Voice of Silence

'What is it you want?' was the first clear idea able to be put into words that he grasped.

Is to suffer not to live?

'What? Not to suffer, to live,' he answered.

And again he was plunged into attention so intense that even the pain did not distract him.

To live? Live how?' the voice of his soul was asking. 'Why, live as I used to live before—happily and pleasantly.'

A true response to the voice of silence

'As you used to live before—happily and pleasantly?' queried the voice. And he began going over in his imagination the best moments of his pleasant life. But, strange to say, all these best moments of his pleasant life seemed now not at all what they had seemed then. All—except the first memories of childhood—there, in his childhood there had been something really pleasant in which one could have lived if it had come back. But the creature who had this pleasant experience was no more; it was like a memory of some one else. (p. 60)

A false response to the voice of silence

'But if one could at least comprehend what it's for? Even that's impossible. It could be explained if one were to say that I hadn't lived as I ought. But that can't be alleged,' he said to himself, thinking of all the regularity, correctness, and propriety of his life. 'That really can't be admitted,' he said to himself, his lips smiling ironically as though some one could see his smile and be deceived by it. 'No explanation! Agony, death... What for?' (pp.63,64)

Ivan listens and begins to hear the meaning of a happy and pleasant life. Yet, Ivan's resentment is *increased* by the awareness that his propriety (from Latin, ***proprietas***, "property")[10] does not seem to have any significance now: he resents that his propriety has left him facing death empty-handed. His proper marriage, his proper manner in court, his proper artifacts at home—one breaks as easily as the other. And they all break at the same time. "We sit like so many spoiled children," writes Boulding, "with all our splintered and lifeless utopias scattered around us like so many broken toys... What is hurting is that it is the day after Christmas, and we have lost our sense of the transcendent."[11] In "bewilderment and anger," Ivan wonders, "Does it really matter at all?"[12] Yet Ivan clings to his standard: he smiles his proper smile.

Against Self and Family

Life is entrusted to each person for good.

'But if it's so,' he said to himself, 'and I am leaving life with the consciousness that I have lost all that was given me, and there's no correcting it, then what?' He lay on his back and began going over his whole life entirely anew. When he saw the footman in the morning, then his wife, then his daughter, then the doctor, every movement they made, every word they uttered, confirmed for him the terrible truth that had been revealed to him in the night.

Recognition of deception as a way of life.

In them he saw himself, saw all in which he had lived, and saw distinctly that it was all not the right thing; it was a horrible, vast deception that concealed both life and death. This consciousness intensified his physical agonies, multiplied them tenfold. He groaned and tossed from side to side and pulled at the covering over him. It seemed to him that it was stifling him and weighing him down. And for that he hated them. (p. 66)

Physical and spiritual agony intertwine.

Ivan is also angry at others. In the morning he sees them, watches them pass by: footman, wife, daughter, doctor. "There is no communication, no reaching out on either side."[13] Physical discomfort is magnified tenfold because no one cares enough to relieve it. Consequently, Ivan hates them because the covering over him is "stifling him and weighing him down." Propriety is stifling him and weighing him down. "Ivan's anger expresses itself in hatred. Hatred expresses itself in denial."[14] Ivan forsakes his propriety but he has nothing else to replace it. He has no other footman, or wife, or daughter, or doctor. Ivan is alone.

The Minister Gives Hope

Doubt causes suffering. Hope makes the future present; it is appropriate to plan. Details of medical assessment make sense in light of hope.

Life is precious again.

When the priest came and confessed him he was softened, felt as if it were a relief from his doubts, and consequently from his sufferings, and there came a moment of hope. He began once more thinking of the intestinal appendix and the possibility of curing it. He took the sacrament with tears in his eyes.

When they laid him down again after the sacrament for a minute, he felt comfortable, and again the hope of life sprang up. He began to think about the operation which had been suggested to him. 'To live, I want to live,' he said to himself. (p. 67)

Into Ivan's life comes a person who is a symbol of "acceptance as the release from resentment, peace as the release from anger."[15] The priest is an intermediary between God and man. "He gives the opportunity to ask for forgiveness."[16] The sense of reassurance in his presence gives Ivan new courage. The anger that had destroyed hope is dissipated: hope is rekindled. "Hope always implies a superlogical connection between a return and something completely new."[17] "To live, I want to live." This time, Ivan will be Vanya.

From Hope to Hopelessness

Non-involvement

His wife came in to congratulate him; she uttered the customary words and added -

'It's quite true, isn't it, that you're better?'

Without looking at her, he said, 'Yes.'...

Defeat

The expression of his face as he uttered that 'Yes' was terrible. After uttering that 'Yes,' looking her straight in the face, he turned on to his face, with a rapidity extraordinary in his weakness, and shrieked

'Go away, go away, let me be!'

When hope leaves, fear and doubt become terrorists.

From that moment there began the scream that never ceased for three days, and was so awful that through two closed doors one could not hear it without horror. At the moment when he answered his wife he grasped that he had fallen, that there was no return, that the end had come, quite the end, while doubt was still as unsolved, still remained doubt.

Hopelessness

'Oo! Oo-o! Oo!' he screamed in varying intonations. He had begun screaming, 'I don't want to!' and so had gone on screaming in the same vowel sound—oo! (pp.67,68)

Ivan's wife has "no ability or desire to support him."[18] She fills the empty silence with empty words. Thus, in the presence of each other, Ivan and his wife are each alone. "The peace and hope that had just been received sacramentally through one who symbolized the Sacrament of Life, seems to be snuffed out so easily," Rev. Dr. Leadbeater says. He shares the experience of a friend, dying of brain cancer, who asked for "'all the help I can get, not just one moment.' His hope was nourished daily by loving family and friends. He died hopefully. The more daring the hope, the more imaginative the hope, the more we can face the future."[19] There is no daring hope for Ivan. He is a man with-out community. Even the sound of his last cries are shut out. There are two doors that bar the way: one is Ivan, the other is his family and friends.

The Miracle of Forgiveness

Experiencing forgiveness	At that very moment Ivan Ilyitch had rolled into the hole, and caught sight of the light, and it was revealed to him that his life had not been what it ought to have been, but that could still be set right. He asked himself, 'What is the right thing?'—and became quiet, listening. Then he felt someone was kissing his hand. He opened his eyes and glanced at his son. He felt sorry for him. His wife went up to him. He glanced at her. She was gazing at him with open mouth, the tears unwiped streaming over her nose and cheeks, a look of despair on her face. He felt sorry for her.
Forgetting self	"Yes, I'm making them miserable,' he thought. 'They're sorry, but it will be better for them when I die.' He would have said this, but had not the strength to utter it. 'Besides, why speak, I must act,' he thought. With a glance to his wife he pointed to his son and said -
Expressing forgiveness	'Take away... sorry for him... And you too. ...' He tried to say 'forgive,' but said 'forgo'... and too weak to correct himself, shook his hand, knowing that He would understand whose understanding mattered. (p. 69)

"Bunyan wrote, 'One seeks the light over the wicket gate.'"[20] Ivan asks, "What is the right thing?" and enters the gate. He listens for the voice of God; he ceases to pity himself. Ivan comes through resentment, anger, hate, denial: the touch of hope, received in the Sacrament, rekindles faith.[21] And faith asks forgiveness. Ivan expresses sorrow for those he once denied. Through his difficult journey, Ivan has gotten free of his propriety. He has found that hope is an interaction "between him who gives and him who receives. This exchange is the

mark of all spiritual life."[22] Vanya lives.

Set Free

Set free to serve.	And all at once it became clear to him that what had tortured him and would not leave him was suddenly dropping away all at once on both sides and on ten sides and on all sides. He was sorry for them, must act so that they might not suffer. Set them free and be free himself of those agonies. 'How right and how simple!' he thought. 'And the pain?' he asked himself. 'Where's it gone? Eh, where are you, pain?'
	He began to watch for it.
Set free from the fear of pain	'Yes, here it is. Well what of it, let the pain be.'
Set free from the fear of death	'And death. Where is it?'
	He looked for his old accustomed terror of death, and did not find it. 'Where is it? What death?' There was no terror, because death was not either.
	In the place of death there was light.
	'So this is it!' he suddenly exclaimed aloud.
Set free for joy	'What joy!' (p. 69)

The question, 'What is the right thing?' has become a hopeful quest. As Ivan is swallowed in light, he realizes that there is more to his wife and son than propriety because he has found more than propriety in himself. On his death-bed, Ivan wants to "set them free." And suddenly, the pain and death that had harrassed him become companions of light: pain reminds him he is still on this earth; death reminds him he is not long for this earth.

The Meaning of the Last Moment

(How does the meaning of an instant **suffer** *change?)*	To him all this passed in a single instant, and the meaning of that instant suffered no change after. For those present his agony lasted another two hours. There was a rattle in his throat, a twitching in his wasted body. Then the rattle and the gasping came at longer intervals.
Life is over	'It is over!' some one said over him.

What is over? He caught those words and repeated them in his soul.

Ivan has already died to falsity, propriety, hatred, doubt 'Death is over,' he said to himself. 'It's no more.'

He drew in a breath, stopped midway in the breath, stretched and died. (pp.69,70)

Someone is eager to announce the end. Ivan takes the words into his soul. There they are transformed: the 'It' that has pursued him is light. Ivan's question, "What is the right thing?" has been a steadfast search through his relationships for what is life. Through the questioning, he has let go of the things that have kept him away from home. "Death is over." Vanya has come home. Death is over. Vanya has come home.

Second Reflection: On Themes of Letting Go of the Things

Caius to Ivan

Kiseveter's syllogism is true (correct) and the closure effected by its logical structure is an achievement that Ivan prizes in his profession. But the generalization, "All men are mortal," does not respond to the question of justice, Why ought "all men" die? Also, there is no life in the abstraction, "Caius is a man"; there is no memory of a man. Ivan is a man with memories. Why ought Ivan die?

Moments to Memories

We distil moments into memories. "What is past has been saved and rescued by us into the past."[23] These memories bear no claim to fame or glory; these memories witness to an 'ordinary' life touched with mystery and beauty, as momentary as the perfect snowflake melting on my jacket.

In the moment of death, memories die. Though the aging grandfather tells his grandaughter his memories, he knows she is too young to remember since yesterday is already a sleep away. And so, the treasures found in life are hid in death. But they are not lost. The child remembers her grandfather by her love, the heart of her memories of her moments with him.

And she remembers that he told her his memories.

Invalid to In-valid (L. *in*-"not"; *validus*-"strong")

The invalid must be strong to keep from becoming in-valid.[24] "It is necessary to maintain an attitude of everyday banality," Aries writes. " On this condition, the sick man may be able to maintain his morale. He needs all his strength to do this."[25] Though Ivan sees his personal and professional life by a different light, (the light of death) he continues to speak as if he possesses command of his legal and household matters. Self-sufficiency is the boundary beyond which he would not let colleagues or family pass. "He does not give way, he guards his secret suffering."[26] Nevertheless, he is possessed by the hour of his suffering; he is at stake in the hour. Ivan's hour of suffering is also the "the hour of the world."[27] How could one alone bear the hour of the world in the hour of personal tragedy?

Ivan is alienated from the hour of the world because he is alienated even from his own family. "He saw that no one felt for him because no one even wished to grasp his position."[28] Yet his illness makes him dependent on them for their care. But how to care for a self-sufficient man? He is "simply ill," they tell him, "need only keep quiet... follow the doctor's orders... [eat] sturgeons for dinner." He hears the self-sufficiency he has bounded his life by parrotting him in the voices and manner of his family. In the hour of his need, the family members 'make' him an invalid while invalidating his experience of suffering and dying.

Dis-ease to Disease

"For Ivan Ilyitch, his illness is suddenly a case that has a separate existence and must have a name. What name? It is up to the doctor to say it, and then he will know whether or not it is serious."[29] Ivan knows his illness as suffering (dis-ease); the doctor knows Ivan's illness as organic malfunction (disease).[30] The doctor has a name for the malfunction. There is no name for the suffering. So the name of the disease puts the dis-ease in perspective. Is Ivan seriously ill? Will he get better? Or is he "terminally ill"? These are the "real question[s] of life and

death"[31]—the questions of dis-ease which the diagnosis of disease answers.

Pain to Despair

Ivan experiences pain as an absence of all that made him satisfied in life in a way which puts him in question. The presence of pain is cruelty, punishment, senselessness. His response to pain—despair, is a recognition that he is not the center of existence, that the center to which he had drawn all things is empty. Ivan despairs of God, because he despairs of himself. "Despair asserts that God has withdrawn himself from me, asserts a reality I do not possess"[32] because there is nothing apart from God. Yet Ivan finds nothing good in himself or in the world he has fashioned. Deceit is at the very heart of it. How could God dwell there?

Help to Hope

The Needy Master

The hour flows through Ivan in the way he lives the hour.[33] Gentle and honest is the hour of his greatest suffering when his servant, Gerasim, is near. With Gerasim, he does not mask his need because Gerasim is one who recognizes him in his need.

> To recognize the Other is to recognize a hunger.To recognize the Other is to give. But it is to give to the master, to the lord, to him who approaches as "You" in the dimension of height.[34]

For Gerasim, the hour of the world, Ivan's hour of suffering, and his own being as a mortal are one. "We shall all of us die so why should I grudge a little trouble?"[35]

Hope is a Promise of Help

The "need for some hope illustrates that life hangs on fragile threads of promise from one person to another."[36] Though Ivan's doctor does not name the disease (that remains a silent battle inside Ivan), there is a "thread of promise" in the doctor's "serious, but not... hopeless face," and in his word, a "chance" of recovery.[37] The minister, however, gives Ivan

the "hope of life"[38] in the Sacrament—the assurance that God dwells with him through the atoning death of Christ, the assurance that life is worth living. Anchored in this hope, the doctor's "chance" becomes Ivan's plan for surgery and after, a commitment to live through pain.

Judgment to Mercy

Ivan had judged his wife and family according to his judgment of himself. Set free from self-condemnation to die in peace, he longs to free them from his condemnation. However, even as he entrusts his death to God, he entrusts their life to Him, for he could not say the word, forgive. "He tried to say 'forgive,' but said 'forgo.'"[39] The tears and grief of his wife and son 'speak' their forgiveness and love at parting. Would they ponder his last word to them? Would they forgo the things of life to find the meaning of life? Would they treasure each other?

All Moments to the Last Moment

> And calmest thoughts come round us— as, of leaves
> Budding,—fruit ripening in stillness, —autumn suns
> Smiling at eve upon the quiet sheaves,—
> Sweet Sappho's cheek,—a sleeping infant's breath,—
> The gradual sand that through an hour-glass runs,—
> A woodland rivulet,—a Poet's death.[40]

The meaning of the last moment, the moment of forgiveness, does not suffer change even though time passes. Suffering is not strong enough to take away joy and peace. Suffering, which questioned Ivan's joy and peace in the beginning, has become the place and time of his joy and peace. For if Ivan could not find joy and peace *in* suffering, where could he find it?

Notes

[1] Leo Tolstoy, *The Death of Ivan Ilyitch*, trans. C.Garnett (London: William Heineman, 1915).

[2] G.Marcel, *Homo Viator: A Metaphysic of Hope*, trans. E.Crawford (Chicago: Henry Regnery Co., 1951), p. 83.

[3] Responses to *The Death of Ivan Ilyitch* were developed through dialogue with Rev.Dr.T.L.Leadbeater, retired Anglican minister and hospital chaplain, October 27, 1983.

[4] Leadbeater, 1983.

[5] Leadbeater, 1983.

[6] Leadbeater, 1983.

[7] Leadbeater, 1983.

[8] Leadbeater, 1983.

[9] Ernest Klein, *A Comprehensive Etymological Dictionary of the English Language*, (New York: Elsevier Pub. Co., 1971), p. 35.

[10] Klein, p. 594.

[11] Elsie Boulding, "Learning to Image the Future," *The Planning of Change*, ed. Warren G.Bennis, (3d ed.; N.Y.: Holt, Rinehart & Winston, 1976), p. 435.

[12] Leadbeater, 1983.

[13] Leadbeater, 1983.

[14] Leadbeater, 1983.

[15] Leadbeater, 1983.

[16] Leadbeater, 1983.

[17] Marcel, p. 57.

[18] Leadbeater, 1983.

[19] Leadbeater, 1983.

[20] Leadbeater, 1983.

[21] Leadbeater, 1983.

[22] Marcel, p. 50.

[23] Victor Frankl, *The Will to Meaning: Foundations and Applications of Logotherapy*, (New York: World Pub. Co., 1969), p. 120.

[24] Klein, p.385.

[25] Phillips Aries, *The Hour of Our Death*, trans. H.Weaver (New York: Alfred A.Knopf, 1981), p. 566.

[26] Aries, p. 565.

[27] Martin Buber, *Between Man and Man*, trans. R.G.Smith (London: Collins Clear-Type Press, 1974), p. 89.

[28] Tolstoy, p. 51.

[29] Aries, p. 564.

[30] See Bergsma and Thomasa, *Health Care: Its Psychosocial Dimensions*, (Pittsburgh: Duquesne University Press, 1982), for a sustained discussion of dis-ease in relation to disease.

[31] Tolstoy, p. 56.

[32] Gabriel Marcel, p. 46.

[33] See Maurice Merleau-Ponty, *Signs*, (Evanston: Northwestern University Press, 1964), p. 423, for a phenomenology of "time's synthesis" as the "action of a life which unfolds."

[34] Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, trans. A. Lingis (Pittsburgh: Duquesne University Press, 1969), p. 75.

[35] Tolstoy, p. 51.

[36] Bergsma & Thomasa, p. 165.

[37] Tolstoy, p. 56; Ibid.

[38] Tolstoy, p. 67.

[39] Tolstoy, p. 69.

[40] John Keats, "After Dark Vapours," *The Physician in Literature*, ed. Norman Cousins, (Toronto: The Saunders Press, 1982), p. 384.

Chapter VI

PAULINE ERICKSON: ONE WITH THE OTHER

First Reflection: On *Pauline's Diary*

In 1971 when she was twenty-one, Pauline Erickson was diagnosed as having pulmonary hypertension, a disease that slowly destroys arteries in the lungs causing heart failure. It wasn't until ten years later that the disease became the central fact of her life as she began to require oxygen supply most of the time. Pauline recorded her experience of illness in a diary.[1] Pauline's diary attests to the meaning of suffering and hope, the meaning of one with the other.

Self-pity

How is self-pity honorable?

> December 2, 1980. I always had felt self-pity was a despicable feeling—but no more. True, to be healthy we cannot linger with that feeling. But every one of us has in our lifetime come face-to-face with self-pity. For some it is extremely transient. For others it overstays its welcome. But for some self-pity is an honorable step toward becoming a total person. (p. 12)

No longer healthy, we pity ourselves. Yet self-pity is not despicable, at least for a time, because self-pity is a way of seeking what is lost. We are lost. When we are well, we are embodied in our plans for our future: we make plans as if tomorrow belonged to us, and we, to tomorrow. So our future is as familiar to us as our past and present. When disease strikes, however, we no longer belong in this structure of achievements and expectations. We no longer belong in this world. The body structures our world, lending the room and the bed its sickness; we dwell in a sickroom, a sickbed. But in a sense we no longer belong to our body. We are emptied of all that is familiar. We are a victim of disease. This thought strikes panic in us for the language remembers what we had forgotten: a victim (L. *victima*) was a "beast of sacrifice"[2] in Roman times. We are bewildered. We had been at ease in the body of our daily life, heeding the calling of clocks and appetite and busy-ness. Nothing calls us anymore; neither

the past nor the future, nor clocks or appetite or busy-ness. Dis-ease banishes ease. Self-pity fills the vacuum. Self-pity is the fullness of our sorrow when we are emptied of routine.

Pain

Where is God in the experience of pain? How do we prevent the comfort of God's presence? How do we work through grief?

December 2, 1980. I want to say, God, where are you? But I know you're here with me and that you care. But I hurt. I need you and you're here—but I still hurt. Shouldn't your presence comfort me more than it does? What am I lacking? Perhaps I have to fully work through my grief before the comfort. (p. 12)

The mystery of pain dwells in the roots of our nature, in the history of our bones. If pain were a problem, complete before us, we could attack the problem and solve it. But we try to evade pain. Lindell, a Christian missionary, writes that pain cannot be evaded by "perfume, roses, soft music, as when the undertaker gave me a handful of rose petals to scatter upon the top of a casket at the grave in place of dirt, as I came to pronounce the fateful words of God: 'You are dust and to dust you shall return.'"[3] Yet the cry of pain, "I hurt," inclines us towards the face of God. Never did God seem nearer, or further away. "In Him, we live and move and have our being."[4] The breath of life that is in us is His breath. Our hurt is His hurt. So we look to the omnipotence of God. This is the nearness, and the distance, of God. And we look to the image of His Son dying on a cross. This is the nearness, and the distance, of God. To look to God is to focus our wanderings into the pathway of a journey. The pathway re-orients us to our past, our present, our future. We no longer pity ourselves: we grieve. The Latin word for grieve, *grâvure*, means to "charge with a load, burden, weigh down."[5] Not only do we look back and mourn the loss of the unity of will and action, the oneness of spirit and body. We take up the burden of journeying while being bound in pain. Our conflict becomes our comfort: pain cannot destroy us. The mystery of pain beckons us to search for abundant life.

Blessings

We are blessed in the measure we are willing to receive blessing.

January, 1981. Dear God, thank you for giving me the tools to see my life beyond my illness, in spite of my illness, and the ability to love life even though I am unhealthy and may die in the not-too-distant future. Granted, I still get jealous of healthy, productive people—but not despairingly so, for there are things in my life I feel very blessed to have. (p. 12)

Illness is not everything. The pain of illness reminds us of our dying body. But this pain also reminds us of our blessings, the good things in life that we often take for granted. We see the dew on the roses on a sunlit morning. We hear the laughter of children at play. A smile delights us. A sunbeam intrigues us. These "little things"[6] nourish our being, giving us food for thought during the long hours of our illness. We do usually measure life by physical activity and productivity: working, shopping, exercising, eating, playing, studying. So we feel jealous of all exuberantly healthy people we meet. But we slowly learn that our attitude transforms small joys—including the busy joys of those around us—into lasting treasures. We are blessed.

Changing

The daily life of illness is a struggle towards unachievable expectations.

March 9, 1982. I look around at this world and feel sad—sad because I'm not "intensely aware" of my life and the beauty of it; of its miraculous nature. I've read that when one faces death, one becomes radiantly alive. Something is wrong here... With all the things going on in this world, all the things needing to be done, all the people suffering, I "should" be focusing on something besides TV.

The daily life of illness is an acceptance of the gift of the day.

I do want to leave something to the world, but I have so little energy. And most of the energy I have to spare is directed to Brian. I love him; I'm going to miss him; I want to be with him every waking moment until I die. Yes, I can hear the birds chirping and smell the flowers. It's wonderful to be alive. (p. 13)

Searching for abundant life, we expect change in ourselves. We are saddened by the reality of our daily existence. Disease seemed to strike us down in a moment: illness lasts a long time; long enough to live with it, long enough to die. Each day of living is a day of dying. And every way of living is a way of dying. "Pain and death," Lindell writes, "are something we do."[7] How we 'do' pain and death—our daily life—becomes our work for those we love. Even

so, times are. We remember the illness at times; we are dis-couraged and im-patient. And we forget the illness at times; we live through it. Through it all, we are changing: we are the world in pain. All that suffers is ours, not only as a way of having, but as a way of being—a way of doing. Pain is our valley and hope is our mountain, and silence surrounds all and fills all. And we respond to the song of the birds with wonder-ful attention. Each of our days is an invitation to live as though it were our dying day.

Giving

To live is to give.

What can we give that means something?

March 13, 1982. Dear God, please help me to live long enough so I can help and touch more people's lives. I am your servant. Please help me to truly relinquish all foolish claims to be in control of my life! I want my life to mean something, and it only can when I is i, and i let you be rightfully in charge. (p. 13)

To be the world in pain is to quell I, to be i: one of one and one and one. As one, even one, the experience of illness is transformed from 'Why must I suffer and die?' to 'Now is my turn to suffer and die.' We resist the I that wells up in resentment to the illness, and therefore, to the kindness that is community. We cannot understand how pain serves to accomplish God's purpose of the good. But each of us remembers how the life of one in pain gave us courage to continue our journey. We help each other. Each life is a gift of life to Life.

Transcending Captivity

Escapism leads to depression.

Thankfulness for faith, hope, love, enables acceptance

April 2, 1982. When I become "seriously" ill, will I continually be depressed because my little mental game can no longer bolster me? After a bit of trepidation, I can answer a hopeful no... I have my belief and faith in God, who gives me courage and, more importantly, love. I love Brian. Our love is everlasting. I have the love of my family, the love of my friends. I am truly blessed. I have been to the mountaintop. Life is beautiful: it hurts but I can leave it. (p. 14)

"Experience is not so much an absorbing into oneself of something as a straining oneself towards something."[1] Experience is an openness to more experience, even when the typical experience of physical movement is so difficult that our own body becomes an object

for us. We will that the body move, but the body resists our intention. When we try to draw the hand towards the face to wash or feed ourself, we experience the weakness of damaged muscles. The hand never reaches the face. It is incapable of doing what we ask. We bolster our hope for physical recovery by testing our endurance each day: we sit up for an hour; we walk a few steps. Though we persist, our body remains an obstacle in the gestalt of daily life. Our will must be actualized through something other than physical movement. Experiencing the body as a captivity, we look to "the shining of that veiled mysterious light."[9] Always, at the end, there is no end. The body, after all, is not the source or limit of our being.

Hope

The meaning of hope is bound up with the events of Easter.

April, 1982. Happy Easter! This Sunday is such a day of jubilation—Christ lives! In the mode of the sermon I heard today, this weekend is a microcosm of life. Friday—despair, desolation, heartbreak, hell, and death; Saturday—loneliness, grief; Sunday—joy, happiness, life anew!

Illness is a time to prepare for Easter in our own lives.

Brian, if you must face my death, remember Friday. It will be hell. But Saturday you will be able to live through—because of God's love you can do it... (We have something so special—I hope it lasts much longer. But if not, we have had 10 beautiful years.) Sunday, Brian, you will be happy. You will always miss me, but that does not mean missing out on life. (p. 14)

"Remember Friday. It will be hell." All through life there is the pain caused by the thought of death because we yearn to live on. An heroic attitude to death by-passes the nature of pain and death. Heroism denies our personal existence: we, too, must die. Weeping bears witness to our personal existence. When we weep, we stand outside what is happening to us. But we cannot always weep. So we surrender to pain as a condition of life. We experience the "whole extent" of its destruction.[10] We experience our mortality. Thousands of years ago, the psalmist wrote,

> The years of our life are threescore and ten,
> or by reason of strength fourscore;
> Yet their span is but toil and trouble,
> they are soon gone, and we fly away.[11]

We know life one day at a time. Would we know the grief and loneliness of Saturday if our heart did not break on Friday? Would we know the joy of Sunday if we did not journey through Friday and Saturday? We know that a seed lives again as a seedling. Is our destiny less than that of a seed? In humility, we hope for the joy of Sunday. There can be no humility—no hope—except through the temptation to despair: the humility of hope is "a response to the infinite Being to whom it is conscious of owing everything that it has and upon whom it cannot impose any condition whatsoever without scandal."[12] Friday... Saturday... Sunday... "You will miss me but that doesn't mean missing out on life." Hope is stronger than death.

Hope for Tomorrow

What are we asking when we ask God to heal us?

April, 1982. Dear God, I do not want to die. Please help me to hang in there until (and after!) the surgery. I adamantly believe in your power to heal people. If it's your will, please heal me. God, don't take me from Brian, not yet. (p. 14)

A funeral cortege slowly drove towards the cemetery. Impatient motorists sped past the procession. A few motorists drove slowly behind and so became a part of the procession. At the cemetery gate, they continued on their way. We do not want to die. We who race against death do not want to die. We who acknowledge death do not want to die. We who are ill do not want to die. We who are healed do not want to die. We do not want to die yet.

Peace

Need to be alone means to be with a loved one, with a book, with God

April 29, 1982. Am I dying? Yes, I feel it. Also the aloneness (of my own doing), except for Brian. I want to be by myself and meditate. Brian gave me an excellent book by Meister Eckhart, a 13th-century Christian mystic. It has made me feel so inadequate, but I feel I am getting deeper in my soul and becoming more in tune with God.

Need to seek peace takes precedence over other needs

I hope I will thank, either verbally, or by letter, the wonderfully caring, supportive, and love-filled friends I have here... But right now I have to focus more on my inner life and peace... (p. 14)

Whenever we try to understand ourself, "the whole perceptible world comes too, and with it comes the others who are caught in it."[13] Even when we are deeply alone, companions come along—other travelers, present and past, whose words speak to us. Thus, the fabric of our human experience draws us deeper into ourself. Gustave Thibon writes, "If you fly away from yourself, your prison will run with you and will close in because of the wind of your flight; if you go deep down into yourself, it will disappear in paradise."[14] Our paradise is peace in the midst of pain and death. The Latin word for peace, *pacem*, means to make a treaty. Life costs us pain and death. Life gives us peace.

Hope for Today

Concern centers on others.	May 22, 1982. I'm alive now. Please help me make the most of it, Lord. I do not want to spend what might be my last days bitter, depressed, or sullen. I want to leave Brian with good remembrances of me.
Reflection leads to deeper understanding.	I do not seem to laugh anymore. Is it because I get out of wind, or is the great expert on death and dying having trouble coping? Whatever the reason, I want to leave with a smile on my face.
God suffers	My theology, please don't desert me now. It would be much easier to be a radical right-winger—to say this is all God's will. But I believe that God doesn't cause suffering and that many times God doesn't interfere. Thus, if I am dying, let God's tears be enough. It is enough.
Life and death intertwine.	God, please make my heart less heavy. Is the burden death, or is it lethargy from illness?
Life is an individual journey.	God, I want to be like Eckhart and say, "Your will be done." But I don't want to die. I just want to talk to you about my tears. (p. 15)

We say, "I'm alive now," with feeling, as we struggle to move, to breathe. For life is more than the body yet bound to the body. We do not have the stamina to laugh and to weep—we find almost no avenue for expression through our body. In this moment of tension between life and death, this last moment, there are no trumpets sounding. Only "I'm alive now," a

pronouncement of the existence of one, an exclamation that fades like a sigh. Our life, still recognizable to others as this dying body, is known to God as this "dying heart."[15] This dying heart, so heavy within us. And pain in this heart, which made the breach between will and action, begins to make one again. "For where was my heart to flee for refuge from my heart?"[16] We do not want a sullen heart, or bitter, or depressed. We want a heart like the heart of God, a heart that is willing to die. Yet we struggle to be born into a life of illness, to be born to die. For still the day calls us, calls us to join in the celebration of life. And still, the celebration re-calls us, re-calls us to the remembrance of our death. And still, so still, the day of our remembrance. Death is silent still.

Second Reflection: On Themes of the Struggle to be Born Into a Life of Illness

Self-pity is Honorable as a Step Away From Self-pity

Self-pity is capitulation to illness. In fighting against capitulation, we learn what we are fighting for. David Cornelius describes his fight against capitulation when he experienced bone cancer at age eight.[17] His description, written in highschool, highlights three moments in the experience of self-pity as an honorable step away from self-pity:

i. the medical diagnosis and the response to the diagnosis;

ii. help to live through the diagnosis and response to the help;

iii. out of (ii.) a third moment emerges, an acceptance of illness as life for "me."

Italics in the quotations from David's writing have been inserted to indicate David's responses to his experiences.

> (i.) The staff at Egleston found the cancer and although they said I was lucky to have it diagnosed so quickly, *I didn't feel lucky.* There was a possibility, they said, that my left arm would have to go. *Why me? What had I done to deserve this?*

> (ii.) At Egleston, a nurse came and helped me to write a list of all the good things should worse come to worst in the pending operation. *Before I realized what was happening, I was feeling both happy and relieved.*

(iii.) *She helped me to discover how fortunate I was that my writing hand wouldn't be affected and that at my young age adjustments would be much easier.* Then the cards started coming. *Although I found solace in each of hundreds that I received, one in particular filled me with wonder.* It told me to read Psalm 6. *I read the whole passage but it was verse two that gave me comfort:*
Have mercy upon me, O Lord; for I am weak: O Lord, heal me; for my bones are vexed.
I had the odd sensation that the David of long ago had written this verse just for me, a small child with bone cancer who wanted to be healed and needed God's mercy.

The medical diagnosis brought a response of self-pity, "I didn't feel lucky... Why me? What had I done to deserve this?" The experience of self-pity became a concerted fight against self-pity through the help of a nurse. He responded by "feeling both happy and relieved." This response was an acknowledgement that "she helped me to discover how fortunate I was." Within his being was the possibility of living with illness. He was also supported by his friends who assured him of comfort, love and faith. Within his community was the possibility of living with illness.

The Pain of Illness

The Pain of Illness is Loss

The possibility of amputation held out a slim possiblity of not-amputation. David clung to this possibility.

After a chaotic week of testing, a surgeon informed me that a crucial biopsy would be done the next day during which the decision would be made as to whether or not they would immediately amputate my arm. *The next morning, nervous and in a fog of sedation, I saw the operating light, its cold steel gleaming down on me before I went under.*

When I came to, my heart leapt! I could feel my arm! It was still there.

During the surgery, there was one who was praying, keeping vigil at the bedside, the first one to see the truth, the one to bear away the possibility.

Then I looked over at my mother. The expression on her face told me the hard truth. *Suddenly I knew I had been wrong. My mind had tricked me with "phantom pain."* My arm was gone. *That quote from Psalms flashed through my mind:*
"Have mercy upon me, O Lord," and I wondered why such a merciful God would let

this happen.

I was lost, afraid and struggling for something to help me cope. Mom was there. *At that dark time she was the only constant in my life.*

At that "dark time", in the depths of the experience of the loss of a part of himself, David relied on his mother to be the "constant" in his life. She was there with him. It was all she could do. It was enough. As her gesture of grief bears away the possibility, her gesture of love sustains the days of loss.

The Pain of Illness is the Experience of Bearing the Grief as Hope

When David describes his mother's gesture of hope that opens up new possibilities for living, he speaks first of "we," then of "Mom" or "I." This was the time of a mutual venture.

> One day we walked through the hospital garden. It was spring and all the dogwoods stood against the fence in full bloom; squirrels were running around and birds were calling from the trees. *Although, I admit, the garden was small and simple, my mother's words of praise brought out its beauty.* She would point out something and proclaim what a wonder it was. *Through her joyous eyes, I could see all of the wonders with which God had filled the garden.*
>
> *That day, we made a pact to see the garden every time we visited the hospital later on for my treatments, so that I would have happy memories to combat the sad ones.*

The quiet acceptance of the inevitability of return for chemotherapy treatments meshes with quiet gratitude for the inevitability of the return of the seasons. Winter, too, is a season of hope.

We Find Refuge in Blessings

> *I thank God Mom was there.* On all our visits to the hospital, she never gave up. *It must have been hard on her but again she helped me turn to the garden as a refuge.* We stopped entering through the cold front doors of the hospital and started slipping past the small gate into the garden and through the back doors.

The place of refuge was a secret happiness that he would not have known had it not been so very near the place of suffering; a happiness he may have missed had his mother not shared her

sight.

Each of Our Days is an Invitation to Live as Though it were Our Dying Day

David had fought against capitulation to illness. He had fought for life.

> *Then, slowly, a strange desire welled up in me. When I reflected on my life previous to the operation, all I could find was an ordinary boy living an ordinary life—no great accomplishments and no great downfalls. I saw my life now as better, and I decided against staying just level. My grades got better. I joined the band and discovered writing. I found that after going through the operation and chemotherapy, and dealing with my hair loss, I had gained a new self. I started actively living my life—trying to make the best of each and every day.* (p. 9).

Self-pity is a memory, a shed image. Each new day is a possibility. David shows us that something must die to nourish the growth of something else. His story ends with his new beginning.[18]

However, Pauline's illness was one of continual deterioration. Her times of reflection were not *about* pain or illness but *in* pain, *in* illness towards death. Pauline struggled to live fully though she could scarcely breathe. What was her new beginning? She knew life by her love.

To Live is to Give

The presence of one who is loved is the most precious gift of all. For example, Joni Eareckson Tada, who is quadrapelegic, tells how her husband becomes her hands for two hours each week as he tends the garden following her instructions.[19] Could she give as much? To live is already to give. Just listening to her makes one happy. Only Joni could give *her* thankfulness, *her* love for Jesus, *her* humor, *her* art; just as only Pauline could give *her* struggle, *her* strength, *her* faith, *her* hope.

The Body, After All, is not the Source or the Limit of Our Being

> God doth not need
> Either man's work or his own gifts; who best
> Bear his mild yoke, they serve Him best. His state
> Is kingly. Thousands at his bidding speed
> And post o'er land and ocean without rest.
> They also serve who only stand and wait.[20]

Frankl wrote that man's last freedom is to choose his attitude, to choose his own way. For Milton, his own way was God's way for him. He served God by bearing his blindness, by taking for his "ownmost being-in-the-world"[21] an alien place, a place of certain struggle, certain hardship, certain limitation. The pain of blindness "[did] not incapacitate his life as a person."[22] In his blindness, he gave the world "Paradise Lost" and "Paradise Regained."

Hope is Stronger than Death

Hope is the Acceptance of Blessings not yet Received

My sister, Joy, suffered from a debilitating bone disease because of kidney failure and dialysis. Though she could barely walk, she was a full-time student in Education. The time came for her to be a student-teacher. How could she teach children when she could barely walk, when every movement hurt? She prayed for healing. One day, this prayer would be answered and she would know again freedom of movement. But this day, the first day of life in her chosen profession, she awoke with the familiar pain. She wept. Dad comforted her with the promises of God. "God has something good for you there," he said, "but you can't know unless you go." They prayed together. Joy chose to go. The first provision was evident from the car—no stairway into the school. Dad walked with her to the door and opened it for her. Thus far he could go with her and no farther. He stood in the entry and watched her walk away. But God was with her all the way. In the Principal's Office, she met Sister Dorothy, who was also the only teacher as the school would close a year hence when the current grade 3/4 students would graduate.

Sister Dorothy's sister was suffering from bone cancer. How deeply she understood Joy's pain. She helped Joy plan lessons that made the most of teaching possibilities within a limited range of teacher movements. Most of all, she taught Joy what it means to live a life of care with a group of children for whom one is responsible as teacher. The children shared in responsible care. When a classmate was ill, they prayed for his recovery. And they were determined to make Joy a teacher. When the faculty consultant left after observing a lesson, they asked, "Are you a teacher yet?" Joy received her accreditation for teaching.

Joy lived through the pain of that experience in the promise, "Lo, I am with you always, even to the close of the age."[23] What she gave to Sister Dorothy and the children cannot be measured. What Sister Dorothy and the children gave to her cannot be measured. Joy and Sister Dorothy became friends for life.

Hope is the Longing for Healing

What are we asking when we ask God to heal us? Health for Pauline was freedom to breathe with ease. No longer was the sky the limit. The limit was so close to her being, so near to her heart. Yet her diary discloses that the healing she received, though not physical, was real. In Shelley's poem, "To a Skylark," dwells a deep sense of this meaning of healing.

We look before and after,
And pine for what is not;
Our sincerest laughter
With some pain is fraught;
Our sweetest songs are those
that tell of saddest thought.

Yet if we could scorn
Hate, and pride, and fear;
If we were things born
Not to shed a tear,
I know not how thy joy ever
should come near.[24]

Pauline could hear life's poem in the birdsong because her life was the refrain. She accepted each day as life for her, she loved life unconditionally. This acceptance was a question as these

lines from Shelley's poem are a question. Through sorrow, could we learn what is joy? Through illness, what is health? Through death, what is life?

Hope is the Acceptance of What We Cannot Understand

"I want to leave with a smile on my face."[25] Pauline gave God her tears. God gave her a smile. How could there be a smile on her face if there were no smile in her heart? And how could there be a smile in her heart if her heart were not reconciled to smile? Reconciled to God, the giver of life, and the giver of life in death.

We Bear the Grief of Death as Hope

This way that Pauline walked, was the way of one. Yet, through her individual journey, she was bound more closely to the community, those who were willing to suffer and rejoice with her on their individual journeys. Pauline did not want the meaning of her life to be the pain her death caused her community. She left those she loved with a grief that could be borne as hope because of her hope, "Sunday... you will be happy."

Life Gives Us Peace

If I could paint a poem of peace, I would paint a summer evening at sunset, the air still warm, and sweet with the smell of clover. And there, at the edge of the farmer's field, *Scandia*, the church my grandfather helped to build. There I am, too, with my family, watching through the windows as the sun glows the grain and the graves into gold. There in the sanctuary, toil and troubles are beautified as worship and praise before the altar of God. There, in the midst, a place set apart, a poem of peace.

Notes

[1] Cited in Brian Erickson, "With All My Heart," *The Lutheran Standard*, 23 (1983), pp.12-16.

[2] Klein, *A Comprehensive Etymological Dictionary of the English Language*, (New York: Elsevier Pub. Co., 1971), p. 810.

[3] Paul Lindell, *Born to Trouble*, Unpublished manuscript, 1972, p.25.

[4] Acts 17:28.

[5] Klein, p. 323.

[6] J.H.van den Berg, *Psychology of the Sick Bed*, (Pittsburgh: Duquesne University Press, 1966).

[7] Lindell, p. 31.

[8] Gabriel Marcel, *The Mystery of Being*, (Vol. 1), (London: The Harvard Press, 1950), p. 41.

[9] Gabriel Marcel, *Homo Viator: A Metaphysics of Hope*, (Chicago: Henry Regnery Co., 1951), p. 32.

[10] F.J.J.Buytendijk, *Pain*, (London: Hutchinson, 1961), p. 152.

[11] Psalm 90:10.

[12] G. Marcel, *Homo Viator*, p. 36.

[13] M. Merleau-Ponty, *Signs*, (Evanston: Northwestern University Press, 1964), p. 15.

[14] Cited in Marcel, *Homo Viator*, p. 28.

[15] Erickson, p. 15.

[16] Augustine, *Confessions of Saint Augustine*, (New York: Sheed & Ward, 1943), p. 68.

[17] David Cornelius, "I Thought I Was Too Young," *Guideposts*, June, 1984, pp.8,9.

[18] See Alfred, Lord Tennyson, "In Memoriam, A.H.H.," *Tennyson: Selected Poetry*, ed. H.M. McLuhan (New York: Holt, Rinehart & Winston, 1966), p. 120, for a description of change as life from death,

> That men may rise on stepping-stones
> Of their dead selves to higher things

[19] Joni Eareckson Tada, (Televised Billy Graham Crusade, Los Angeles, California, September, 1984).

[20] John Milton, "When I Consider How My Light is Spent," *The Norton Anthology of English Literature*, (Vol. 1), ed. M.H.Abrams, (New York: W.W. Norton & Co., 1968), p. 1015.

[21] See Martin Heidegger, *Being and Time*, trans. J. Macquarrie & E. Robinson (New York: Harper & Row, 1962).

[22] Buytendijk, p. 132,is writing generally about the experience of pain.

[23] Mt. 28:20.

[24] Percy Bysshe Shelley, "To a Skylark," *The Norton Anthology of English Literature*, (Vol. 2), ed. M.H. Abrams, (New York: W.W. Norton & Co., 1968), p. 444.

[25] Erickson, p. 15.

Chapter VII

DOCTOR RIEUX: ONE FOR THE OTHER

First Reflection: On *The Plague*

Albert Camus received the Nobel Prize for Literature in 1957 for *The Plague*.[1] In his acceptance speech, he said,

> For more than twenty years of an insane history, hopelessly lost like all the men of my generation in the convulsions of time, I have been supported by one thing: by the hidden feeling that to write today was an honor because this activity was a commitment—and a commitment not only to write. Specifically, in view of my powers and my state of being, it was a commitment to bear, together with all those who were living through the same history, the misery and hope we shared.[2]

Plague is a life of misery, and hope. The novel, *The Plague*, describes a profound test of human being, a situation that relentlessly requires the "chosen one" to be "for the other."[3] The novel is set in Oran, a large French port on the Algerian coast, where Camus lived for a year and experienced plague. Doctor Rieux, the narrator in the novel, is a citizen of Oran. Tarrou, his friend, is a visitor to Oran who is compelled to stay in the city when the gates are closed because of plague. Doctor Castel researches for an anti-plague serum. Paneloux is the priest.

The Fact of the Doctor's Diagnosis

Pity satisfies when it is tied to useful action.

"Have some pity, doctor!" It was Mme. Loret, mother of the chambermaid at Tarrou's hotel, who made the appeal. An unnecessary appeal; of course he had pity. But what purpose could it serve? He *had* to telephone, and soon the ambulance could be heard clanging down the street. (At first the neighbors used to open windows and watch. Later they promptly shut them.)

Hope resides in the person of the doctor.

Then came a second phase of conflict, tears and pleadings—abstraction, in a word. In those fever-hot, nerve-ridden sickrooms crazy scenes took place. But the issue was always the same. The patient was removed. Then Rieux, too, could leave.

... every evening was like that evening when he was called in for Mme. Loret's daughter. He was shown into a small apartment decorated with fans and artificial flowers. The mother greeted him with a faltering smile.

"Oh, I do hope it's not the fever everyone's talking about."

The doctor's evidence dispels hope

Grief takes the place of hope.

> Lifting the coverlet and chemise, he gazed in silence at the red blotches on the girl's thighs and stomach, the swollen ganglia. After one glance the mother broke into shrill, uncontrollable cries of grief. And every evening mothers wailed thus, with a distraught abstraction, as their eyes fell on those fatal stigmata on limbs and bellies; every evening hands gripped Rieux's arms, there was a rush of useless words, promises, and tears; every evening the nearing tocsin of the ambulance provoked scenes as vain as every form of grief. (p. 54)

Pity is useless. Grief is useless. Neither pity nor grief changes the situation. Yet we pity. We grieve. Pity and grief change us, and we see the situation differently. "Everybody knows that pestilences have a way of recurring in the world; yet somehow we find it hard to believe in ones that crash down on our heads from a blue sky."[4] We know that pestilences scourge faceless masses. But these faces are familiar, these lives are precious; the chambermaid at Tarrou's hotel is Mme. Loret's daughter.

The fear of plague turns us cold, colors us grey. So we shut our windows against it. Yet, the cold greyness of the fear of plague calls us to suffer pity, to suffer grief; to suffer our human being. The cold greyness of the fear of plague brings us to live what we cannot reason out. Thus, we pity Mme. Loret for her daughter's sake. And we grieve for Mme. Loret's daughter for her mother's sake. Through their suffering, we remember that there are no faceless masses, only individuals who suffer and rejoice as we do. This, too, is life. And life is dear to us.

The Doctor Finds Solace

How do we experience pity when it is not tied to useful action?

> One grows out of pity when it's useless. And in this feeling that his heart had slowly closed in on itself, the doctor found a solace, his only solace, for the almost unendurable burden of his days. This, he knew, would make his task easier, and therefore he was glad of it. When he came home at two in the morning and his mother was shocked at the blank look he gave her, she was deploring precisely the sole alleviation Rieux could then experience. (p. 54)

How long can we pity? How long can we grieve? How long before our tears break one last time?

All streams run to the sea,
but the sea is not full;
to the place where the streams flow,
there they flow again.
All things are full of weariness
a man cannot utter it.[5]

With a "blank look," a weary doctor asks, "Why?" Camus writes, "everything begins in that weariness tinged with amazement." The weariness comes "at the end of the acts of a mechanical life, but at the same time it inaugurates the impulse of consciousness."[6] Weariness inaugurates the impulse of consciousness of community. We all alike must suffer. We all alike must die. We all alike must ask, "Why?" The weariness is pervasive. "All streams run to the sea but the sea is not full."

The Meanings of Being a Doctor

Achievement is one of the meanings of being a doctor.

Death is one of the meanings of being a doctor.

"When I entered this profession, I did it 'abstractly,' so to speak; because it meant a career like another, one that young men often aspire to. Perhaps, too, because it was particularly difficult for a workman's son, like myself. And then I had to see people die. Do you know that there are some who *refuse* to die? Have you ever heard a woman scream 'Never!' with her last gasp? Well, I have. And then I saw that I could never get hardened to it. I was young then, and I was outraged by the whole scheme of things, or so I thought. Subsequently I grew more modest. Only, I've never managed to get used to seeing people die. That's all I know."

[Tarrou is speaking]... "I now can picture what this plague must mean for you."

The doctor feels personally responsible for death.

"Yes. A never ending defeat."

Tarrou stared at the doctor for a moment, then turned and tramped heavily toward the door. Rieux followed him and was almost at his side when Tarrou, who was staring at the floor, suddenly said;
"Who taught you all this, doctor?"

Suffering defeats the doctor

The reply came promptly:

"Suffering." (p. 73)

Doctor Ulan' says that the high profile, respectable status of the medical profession calls young people to its practice. The medical profession is a challenge. However, the challenge of the medical profession is only partially fulfilled through the challenge of academic competition or the challenge of brilliant diagnosis. The fundamental challenge of the medical profession is the ill and dying patients whom the doctor cares for. The doctor cannot be trained to make an adequate response to this challenge: the doctor learns to respond to this challenge by living through many difficult experiences. Reflecting on these experiences, the doctor tries to overcome what he or she perceives to be personal or professional deficiencies.

Yet we must not separate the personal and professional aspects of the practise of medicine as if the doctor could be 'entirely professional' or 'too personal.' The profession of medicine involves the person, the person is mediated through the profession. So death is not a "never ending defeat"; the doctor, too, must die. "The doctor experiences life's events with the patient, including death."[1] The doctor can help the ill and dying to the limit of his or her professional care. Suffering is the meeting-place, the place where doctor and patient share the ache of all human existence. Suffering is the meeting-place, the place where doctor and patient share the hope of all human existence. "There is no cure now but there will be someday."[2]

To Have a Heart for Healing and No Cure

The doctor diagnoses disease in order to cure. What is it like for the doctor when there is no cure?

He knew that, over a period whose end he could not glimpse, his task was no longer to cure but to diagnose, detect, to see, to describe, to register, and then condemn—that was his present function. Sometimes a woman would clutch his sleeve, crying shrilly: "Doctor, you'll save him, won't you?" But he wasn't there for saving life; he was there to order a sick man's evacuation. How futile was the hatred he saw on faces then! "You haven't a heart!" a woman told him on one occasion. She was wrong; he had one.

To have a heart means to endure, to start each day anew.

It saw him through his twenty-hour day, when he hourly watched men dying who were meant to live. It enabled him to start anew each morning. He had just enough heart for that, as things were now. How could that heart have sufficed for saving life? (p. 101)

Neither the populace nor the medical community understood plague. People died within a few days with the plague because early indicators were not recognized and doctors were

attempting to develop antibiotics as the plague raged on. Thus, the experience of plague in the novel is analogous to the diagnosis and treatment of some types of cancer today.[10]

The doctor speaks the word: "Cancer." How much heart does a doctor need to pronounce the word, to live that eternal moment with the patient? That moment that robs the future of its promise, the past of its fulfillment, the present of its living action. All is reflection now. But there is not time for reflection. All is regret now. But there is not time for regret. We must get to the business of dying. Through the thick fog of all the possibilities and the never-to-be-achieved, the patient acknowledges the verdict. Does the doctor share the numbness? Does the doctor have a heart? "Yes," says Doctor Ulan, but is there enough heart to cope with anything beyond that word that ends the day? Is there enough heart to re-turn to hospital rounds and office appointments and the choice of wallpaper for the living room?[11] Is there enough heart to continue to live as if the day had not died the moment—the eternal moment—the word was spoken? How can there be enough heart? And yet, the doctor and the patient do continue as if that eternal moment did not hold sway.

--Life and the Doctor of Death

The doctor who brings grief is the doctor of death.

The doctor is also made of dust.

The doctor restrains his pity when he is with the patient.

Before the plague he was welcomed as a savior. He was going to make them right with a couple of pills or an injection, and people took him by the arm on his way to the sickroom. Flattering, but dangerous. Now, on the contrary, he came accompanied by soldiers, and they had to hammer on the door with rifle-butts before the family would open it. They would have liked to drag him, drag the whole human race, with them to the grave. Yes, it was quite true that men can't do without their fellow men; that he was as helpless as these unhappy people and he, too, deserved the same faint thrill of pity that he allowed himself once he had left them. (p. 101)

Doctor Rieux continually dealt with the consequence of plague: death. The doctor became the symbol of death to the families who could not escape the presence of plague in their homes: they could not escape the doctor of death. Consequently, the doctor came to represent the patients' disease.[12] In their awesome sorrow, the patients' families forgot the comforting presence of the doctor during other trying days, days when illness meant a sensible

prescription: rest in bed, drink plenty of fluids, take one tablet twice daily.

The doctor controls the emotion of pity in order to live the life of pity. But who pities the doctor? The doctor himself needs a physician. "Is there no balm in Gilead? Are there no physicians there?"[13] The doctor shares with the priesthood the profession of giving.[14] But the doctor does not necessarily share the minister's source of strength. The minister offers salvation. The doctor offers "some good life" during a difficult time.[15] "Some good life," says Doctor Ulan, means to return to work, for one; to continue education, for an other; to travel, for an other. "Some good life" means that death occurs sooner for these than for the general population. "Some good life" means treating the disease, reducing suffering, or helping the patient cope. "Some good life" means a gift, even if only a respite in the face of death. And, "some good life" is the doctor's reward when death comes.[16] "Some good life" is the physician's healing balm.

The Doctor Fights for Life

A new day.

A time to fight.

A time to die.

A time to "move back."

> Light was increasing in the ward. The occupants of the other nine beds were tossing about and groaning, but in tones that seemed deliberately subdued... Only the child went on fighting with all his little might. Now and then Rieux took his pulse—less because this served any purpose than as an escape from his utter helplessness—and when he closed his eyes, he seemed to feel its tumult mingling with the fever of his own blood. And then, at one with the tortured child, he struggled to sustain him with all the remaining strength in his own body. But, linked for a few moments, the rhythms of their heartbeats soon fell apart, the child escaped him, and again he knew his impotence. Then he released the small, thin wrist and moved back to his place. (p. 112)

Each of us has a place. Regardless of how close the doctor feels to the child, how valiantly he fights against the child's death, the doctor cannot give life. The doctor must keep his place. "Some good life" is *given* and the doctor and patient make the best of it. "Some good life" is taken. And the doctor is left in his place.

The Doctor Questions All Values

What do we lose when we die of plague?

What do we win when we survive plague?

> Tarrou had died this evening without their friendship's having had time to enter fully into the life of either. Tarrou had "lost the match," as he put it. But what had he, Rieux, won? No more than the experience of having known plague and remembering it, of having known friendship and remembering it, of knowing affection and being destined one day to remember it. So all a man could win in the conflict between plague and life was knowledge and memories. But Tarrou, perhaps, would have called that winning the match. (p. 148)

"Winning the match" is a fundamental absurdity. All must breathe and hope. In this sense, all must win the match. Had Tarrou "lost the match?" Or is losing the match a fundamental absurdity too? All must suffer and die. In this sense, all must lose the match. Yet death itself "causes us to question all values."[17] What was first in our life? Friendship? Child? Match point? Death reduces the best of life and the worst of life to knowledge and memories—dust and ashes: death buries life. But death also infuses the best of life and the worst of life with hope: death resurrects life. And each always gives and each always receives, knowledge and memories—and hope. This is the heart of what it means to be a doctor and a patient. This is the heart of pity, (L. *pietas*;"devotion"),[18]the devotion of care.

Second Reflection: On Themes of the Heart of Pity

Science does not Pity

Eiseley[19] has characterized science as a relentless, searching eye, an eye that sees all and sees nothing. The eye sees all because it is without pity, sees nothing because it is without hope. Eiseley was possessed by the eye. As he walked along the coast of Costabel, the eye saw a starfish dead in the sand. The eye understood that the sea had cast it on the shore and the sand had clogged its pores. The eye saw shell collectors, burdened with sacks. The eye understood that the creatures which did not die in the sand would die in the sacks. And the eye saw the cauldrons of boiling water. The eye understood that the creatures which did not die in the sand or the sacks would die in the water. The eye understood the sea and the death and the greed.

For the light in the eye was the observation of survival.

Eiseley walked on. There was one in the distance who gathered starfish and threw them back into the ocean. The eye did not understand the star thrower. And the man possessed by the eye was perplexed.

> Again the eye, the cold world-shrivelling eye, began its inevitable circle in my skull. He is a man, I considered sharply, bringing my thought to rest. The star thrower is a man, and death is running more fleet than he along every seabeach in the world.[20]

Yet the figure of the star thrower at dawn of day evoked memories in the man that the eye did not see, memories of boyhood, disillusion... and the figure of the star thrower evoked speech in the man that the eye could not understand, "I love...the things beaten in the strangling surf, the bird, singing, which flies and falls and is not seen again"[21] ... and the figure of the star thrower evoked action in the man which the eye could not predict, "Silently I sought and picked up a still-living star, spinning it far out into the waves."[22]

Eiseley has described his journey back from observation for its own sake. For him, the eye of (Darwinian) science yielded foregone conclusions: the observation of survival had lost any meaning in the presence of inevitable death.

Science because of Pity

Observation is the keystone of modern medical diagnosis and research. Scientific observation has yielded ways of treating some kinds of cancer, technological advances in dialysis treatment, bone restorative drugs, development in treatment of diabetes, to name a few.[23] These are tremendous advances. Yet illness remains and suffering is increased by some treatments. The patient dies and observation continues. This paradox places us in a question, "Of what rock is the keystone of medical observation quarried?"

The Heart of Pity is "a Sympathy Full of Regret" for "All the Pain"

Doctor Rieux experienced the weariness of pity as the physical and emotional outcome of outrage at the suffering of humanity. His "blank look"[24] was exhausted outrage. Augustine writes, "O foolish man to bear the lot of man so rebelliously."[25] Exhaustion brought the recognition that he could not live in outrage: the "community of suffering"[26] is the "lot of man." Schweitzer writes,

> From this community of suffering I have never tried to withdraw myself. It seemed to me a matter of course that we should all take our share of the burden of pain which lies upon the world.[27]

How does the doctor "take" his or her "share of the burden which lies upon the world" in the context of modern medical science?

The Heart of Pity is the Manner of Care

For Doctor Rieux, the event of diagnostic observation was the official registration of plague in a household enabling the removal of the ill person for the sparing of the family. But the family saw the sparing differently: they would rather care for the one who was ill even if that meant the death of all ("drag the whole human race with them to the grave").[28] Doctor Rieux was the voice of reason among them. His reason was science; their reason was love. His reason was pity; their reason was despair, and hope.

Doctor Rieux shows how diagnosis can be gentled by the heart of pity even during plague. The old family doctor in *Elsie Venner*[29] shows how diagnosis can serve the heart of pity.

> The old doctor was a model for visiting practitioners. He always came into the sickroom with a quiet, cheerful look, as if he had a consciousness he was bringing sure relief with him. The way a patient snatches his first look at his doctor's face, to see whether he is doomed, whether he is reprieved, whether he is unconditionally pardoned, has really something terrible about it. It is only to be met by an imperturbable mask of serenity, proof against anything and everything in a patient's aspect.[30]

The "sure relief"[31] the old doctor brought was hope. Hope resides in the person of the doctor. The doctor is a "symbol of all that is transferrable from one person to another short of immortality."[32] In what sense, then, is serenity a mask? Hope is not a resolution of the situation of conflict but a way of living through the conflict. The doctor restrains the expression of pity to perform the action of pity. Schweitzer writes,

> In vain have I tried to train myself to that equanimity which makes it possible for a doctor, in spite of all his sympathy with the sufferings of his patients,to husband, as is desirable, his spiritual and nervous energy.[33]

Schweitzer speaks of the need for disciplined pity, the pity that learns to abide in hope. Hope is the serenity of pity. Truly, serenity is the gift of hope.

The Heart of Pity is the Mortal Helping the Mortal

Doctor Rieux was waiting for an anti-plague serum to be developed. The first dose he tried on a child who was dying. The child did not recover. Why did Doctor Rieux give the child the serum? To observe the child's reaction? Because he wanted the child to live? These are the questions of plague, the presence of inevitable death.

> "There wasn't any remission this morning, was there, Rieux?"
> Rieux shook his head, adding, however, that the child was putting up more resistance than one would have expected. Paneloux, who was slumped against the wall, said in a low voice:
> "So if he is to die, he will have suffered longer."[34]

Yes, Doctor Rieux wanted the child to live. And yes, he observed the child's reaction. To save the lives of the multitude, he must save *this* life: the advancement of medicine was the life of the child.

There was no division between the doctor and the observer. The child's death gripped Doctor Rieux and made him 'see'. The child's death was a personal loss to Doctor Rieux, and a personal loss to the multitude. In this sense, death defeats the doctor. He lost the child and the multitude: the need remains. Again, there is one in greatest need.

"Will you have to start it [anti-plague serum preparation]?" Tarrou asked Castel. The old doctor nodded slowly, with a twisted smile.
"Perhaps. After all, he put up a surprisingly long resistance." [33]

And the one in greatest need will try the new serum and will suffer—and die, or perhaps, suffer—and live. The multitude waits. Already there is another one in greatest need.

The Heart of Pity is Resurrected by Death

Death brings a challenge with defeat, a commitment: this patient must not die in vain. Doctor Scribner, who pioneered the first dialysis unit in North America, writes of the challenge of a patient's death.

> Mr. Saunders had a disease which had totally and irreversibly destroyed his kidneys. They would never function again.
>
> What to do?...We did the only thing we could do. We had an agonizing conversation with Mrs. Saunders and told her to take her husband back home to Spokane where he would die, hopefuly without much suffering... He died quietly [at home] about two weeks later... The emotional impact of this case was enormous on all of us, and I could not stop thinking about it.
>
> Then one morning about 4:00 a.m. I woke up and groped for a piece of paper and a pencil to jot down the basic idea of the shunted cannulas which would make it possible for people like Joe Saunders to dialyze again and again with the artificial kidney without destroying two blood vessels each time.[34]

There was no division between the doctor and the observer. Mr. Saunders' death gripped Doctor Scribner and made him 'see'. "Pain" writes Levinas, "refers to the joy of living. Already and henceforth life is loved."[37] "People like Joe" live. I am like Joe, I use Scribner's shunt to dialyze. But the doctor is also like Joe, a human being who loves life. The illness and death of the one in greatest need gives life to science. And the heart of pity gives science to life.

Notes

[1] Albert Camus, *The Plague*, trans. S. Gilbert, Nobel Prize Library, *Camus and Churchill*, (New York: Alexis Gregory, 1971).

[2] Camus, p. 8.

[3] Emmanuel Levinas, *Otherwise Than Being or Beyond Essence*, trans. A. Lingis (Boston: Nijhoff, 1981).

[4] Camus, p. 29.

[5] Eccles. 1:7,8a.

[6] Cited in M. Greene, "Cognition, Consciousness and Curriculum," *Heightened Consciousness, Cultural Revolution, and Curriculum Theory*, ed. Wm. Pinar, (Berkeley: McCutchan, 1974), p. 74.

[7] Responses to *The Plague* were developed through dialogue with Doctor R.A. Ulan, Director of Dialysis for Northern Alberta, University of Alberta Hospital, Walter MacKenzie Health Sciences Centre, Edmonton, Alberta, September 28, 1983.

[8] Ulan, 1983.

[9] Ulan, 1983.

[10] Ulan, 1983.

[11] Ulan, 1983.

[12] Ulan, 1983.

[13] Jer. 8:22.

[14] Ulan, 1983.

[15] Ulan, 1983.

[16] Ulan, 1983.

[17] Ulan, 1983.

[18] Klein, *A Comprehensive Etymological Dictionary of the English Language*, (New York: Elsevier Pub. Co., 1971), p. 561.

[19] Loren Eiseley, *The Star Thrower*, (London: Wildwood House, 1978), pp. 169-185.

[20] Eiseley, pp. 172-173.

[21] Eiseley, p. 182.

[22] Eiseley, p. 184.

[23] For an example of life-saving bone restoration research, see Hector F. DeLuca, "The Kidney as an Endocrine Organ Involved in the Function of Vitamin D," *The American Journal of Medicine*, 58, (1975), 39-56, for the biochemist's analysis; Donald S. Siverberg et al., *Canadian Medical Association Journal*, 112, (1975), 190-195, for the medical doctor's analysis; Arthur Olson, "The Olson's Three Miracles," *Reader's Digest*,(August, 1976), pp. 61-66, for Arthur's description of his experience of rising from a wheelchair to walk, move with ease, and conduct his beloved music.

[24] Camus, p. 54.

[25] Aurelius Augustine, *Confessions of Saint Augustine*, trans. F.J. Sheed (New York: Sheed &

Ward, 1943), p. 68.

[26] Albert Schweitzer, *Out of My Life and Thought*, trans. C.T. Campion (New York: Henry Holt & Co., 1933), p. 279. The quotation in the thematic heading is found on the same page.

[27] Schweitzer, p. 279.

[28] Camus, p. 101.

[29] Oliver Wendell Holmes, "Elsie Venner," In *The Physician in Literature*, ed. Norman Cousins (Toronto: Holt, Rinehart & Winston, 1982), pp. 224-230.

[30] Holmes, p. 229.

[31] Ibid.

[32] Norman Cousins, *The Healing Heart*, (New York: W.W. Norton & Co., 1983), p. 128.

[33] Schweitzer, p. 166.

[34] Camus, p. 112.

[35] Camus, p. 113.

[36] Scribner, Belding G. "The Problem of Patient Selection for Treatment with an Artificial Kidney" Unpublished manuscript, 1972, cited by Renee Fox & Judith Swazey, *The Courage to Fail*, (Chicago: University of Chicago Press, 1978), p. 202.

[37] Emmanuel Levinas, *Otherwise Than Being or Beyond Essence*, trans. A. Lingis (Boston: Nijhoff, 1981), p. 145.

Chapter VIII

FLORENCE NIGHTINGALE: ONE BY THE OTHER

First Reflection: On *Notes on Nursing*

Heidegger finds in being there (G. *da-sein*) the essence of human experience. Care is the ***being*** of being there. We are the ***there*** of being there, the place and time where the being of care is revealed through our silence, our speech, our actions.[1] What is it like to choose to be there in a situation of illness, to be there a nurse? Florence Nightingale (1820-1910) chose to be there a nurse in the Crimean War and to fight for the rest of her life for adequate medical care for British soldiers. Excerpts from her own experience, "the small, still beginning, the simple hardship, the silent and, *gradual* struggle upwards," give life to her instructions to student nurses.[2]

What Nursing Does

Memories in action, or Learning from experience

(1897)The relics, the representations of the Crimean War! What are they? They are first the tremendous lessons we had to learn from its tremendous blunders and ignorances. And next they are Trained Nurses and the progress of Hygiene. These are the "representations" of the Crimean War. (p. 425)

Nursing helps nature heal.

Pathology teaches the harm that disease has done. But it teaches nothing more. We know nothing of the principle of health the positive of which pathology is the negative, except from observation and experience. And nothing but observation and experience will teach us the ways to maintain or bring back the state of health. It is often thought that medicine is the curative process. It is no such thing; medicine is the surgery of functions, as surgery proper is that of limbs and organs. Neither can cure, nature alone cures. Surgery removes the bullet out of the limb, which is an obstruction to cure, but nature heals the wound. So it is with medicine; the function of an organ becomes obstructed; medicine, so far as we know, assists nature to remove the obstruction, but does nothing more. And what nursing has to do in either case, is to put the patient in the best condition for nature to act upon him.(p. 110)

"Nursing still does that."[3] The patient is taught the benefit of and procedures for preventative measures, such as hygiene and inoculation, as well as general health care in

response to the disease process, such as diet, rest and exercise. But nursing must also respond to the requirements of increased technology. With dialysis, the process of nature is stopped. With transplantation, the process of nature is reversed. The fulfillment of this paradox is a healthy dialysis person or a healthy transplant person. This intervention into the process of nature requires refined techniques, which in turn require more questions to be asked to ascertain the patient's condition. The nurse speaks a technical vocabulary concerning the disease process, tests and treatment which she explains to the patient in terms of the purpose of the procedure and what the experience will be like.

> Ruth[4] couldn't sleep. She was demanding, grouchy, and nagging. As she began to listen to the nurse's description of her experience in terms of a disease process that many people undergo, the fear of the unknown became a pathway to follow. She began to understand this difficult time as a time for choosing among limited alternatives for a healthful way of living (choosing to follow a restrictive diet, for example). She became aware that she could choose her attitude in all this. She chose kindness, courtesy, consideration.

The nurse cannot change the progression of the disease, but she can help to ease the experience. She can be there, a nurse.

Seeing Illness

Being with the patient is the "praxis" of observation. ("Praxis is thoughtful action—action full of thought and thought full of action." [T.Aoki, 1981, p. 40.])

Nursing has to nurse living bodies and spirits.(p. 412)

The most important practical lesson that can be given to nurses is to teach them what to observe—how to observe—what symptoms indicate medical improvement—what the reverse—which are of importance—which are of none—which are the evidence of neglect—and of what kind of neglect.(p. 88)

The initial months of nurses' training are designed to teach the nursing student to 'see' particular indicators of disease. For example, pallor, swelling, and uremic odor are indicators of kidney disease. But the nurse learns to 'see' the effect of these indicators in the lives of her patients through many experiences. While observational data and skills are first taught and then practised, the teaching of experience begins with the sense that "something is not right"[5] and slowly becomes articulate. The meaning of the indicators of disease in the patient's life is pain.

Shirley sees shallowness around the eyes, greyness in the skin, a grimace when a painful area is touched, lethargy which can be due to the pain of movement, listlessness from the supreme effort to undergo pain. She misses seeing the accustomed gestures, the light in the eyes. In the missing, there is the hope for the return. Can the patient come through the pain? The nurse's presence is the embodiment of that hope.

Light at Night

Night care: Night rounds;

> One of the nurses described accompanying her on her night rounds. 'It seemed an endless walk... As we slowly passed along the silence was profound; very seldom did a moan or a cry from those deeply suffering fall on our ear. A dim light burned here and there. Miss Nightingale carried her lantern which she would set down before she bent over any of her patients. I much admired her manner to the men— it was so tender and kind.'(p. 160)

Night provisions

> A good nurse will always make sure that no door or window in her patient's room shall rattle or creak; that no blind or curtain shall, by any change of wind through the open window, be made to flap— especially will she be careful of all this before she leaves her patients for the night. If you wait till your patients tell you or remind you of these things, where is the use of their having a nurse? There are more shy than exacting patients, in all classes, and many a patient passes a bad night, time after time, rather than remind his nurse every night of all the things she has forgotten. (p. 36)

"It's the little things that count," Shirley says. When giving out medications in the evening, she asks the patient about his or her preference for night care. "A glass of water by the bedside? A light in the room? Shades drawn? Untuck toes? Another blanket?"[6]

Lights dimmed and curtains drawn have a quieting effect for one patient while, for another, bright light is cheering.

> When Jack[7] was dying, he wanted to see things, see people pass by. His wife left at 10:00 p. m. after a twelve hour vigil and the light was his contact with life when she was gone. He waited through the night for the day, the return of his beloved visitor.

The depth of time in the quiet of the night is accentuated or alleviated by the light, the noise of the intercom, the tones of conversation, the sound of footsteps, the nurse come in for night care or to check for night symptoms, such as restlessness and need for oxygen which can

increase in intensity because of anxiety over wakefulness. The hours between 2:00 and 4:00 a.m. are the 'longest.' The patient awake during these hours often tells the morning nurse, "The night was very long."[8] So the patient waits for sleep and for the morning, perhaps for sleep in the morning. The nurse waits for the morning and for the sleep she needs after a night of work.

Bright light is not sufficient to return us to the day. Day is heralded by the hospital clatter. The patient hears time pass with the food wagons, the intercom now in competition with conversation and laughter, the routines. And the patient watches time pass, the nurse's quick gestures and pace, the cleaning staff's activity, and the doctor's rounds. Time skims along the surface of the bustling day and shelters the patient and nurse in its passing.

Perhaps watching and hearing time pass helped Jack recall his time: "I've had a good life. I've raised my children. I've done what I wanted."[9] Time that has passed stands still like the stillness of the wakeful night. Time that has passed becomes a song, and the refrain is sung over and over by those who remember, 'He had a good life.' Happy memories are a light at night for the patient, nurse, and family and friends.

The Presence of Care

In silence

> When such a one [a wounded soldier] looked and saw that the honored Lady in Chief was patiently standing beside him— and with lips closely set and hands folded— decreeing herself to go through the pain of witnessing pain, he used to fall into the mood of obeying her silent command and—finding strange support in her presence—bring himself to submit and endure.(p. 160)

In speech

> What a convenience it would be if there were any single person to whom he [the patient] could speak simply and openly without pulling the string upon himself of this shower-bath of silly hopes and encouragements; to whom he could express his wishes and directions without that person persisting in saying 'I hope that it will please God yet to give you twenty years' or, 'You have a long life of activity before you.' (p. 86)

The nurse and the patient must trust that each other is trying to help. The nurse can speak about a "compliant" or a "non-compliant" patient. The patient can speak about a "judge" or an "empathizer."[10] But the attitude of trust which binds the nurse and patient in a

common endeavor finds expression through the experience of the family. "If my father, my mother, my son, were here, how would I want them to be treated? How would I want to be treated?"[11] And so, the medical significance of the procedure dwells as surely in the presence of care as it does in the promise of medical theory and practise. Paradoxically, Shirley is strengthened to carry out painful procedures by her commitment to the patient *as if* he or she were a family member. This care, she in turn must give over to other professionals when members of her own family are ill—her senses dulled with her own pain, she could not carry out her nursing responsibilities. The abiding *as if* is a condition for nursing care.

Yet, this *as if* does not automatically establish trust between the nurse and the patient. "How it comes about, I'm not sure," says Shirley, but she recognizes trust in silence, and in speech, even in the tone of speech.

> Sometimes silence is a comfort. You don't have to say things to fill the silence. Sometimes just sitting by a patient's bed, holding a hand—there is a lot of comfort in that which you cannot speak. Bring in a hot water bottle without being asked, pull the blind. Just a feeling of trust.[12]

Other gestures shared in silence 'speak' trust—the invitation of a smile or outstretched hand, a reassuring pat, a wink, a wave. But Shirley speaks of the other silence, too, the silence where these gestures are witheld or ignored, the silence that needs speech.

> Another nurse and I went in to see a young man who was distressed about his disease process. The curtains were drawn around his bed with the light over the bed off. Also, he didn't have the light on in the room. He had his T.V. set plugged in. We couldn't get a "yes" or "no" answer out of him. We asked him how he felt about his kidney disease. He took a long time, he didn't tell us quickly... The next night we went in, the curtains were open and the lights were on in the room but not over the bed. We talked a bit more...[13]

In this situation, speech was the purveyor of trust. "Sometimes, people who go into themselves don't really wish to be alone, they just don't know how to approach you about how they are feeling."[14] This young man spoke out of a history of misfortune. He had lost his job and now, his health. How would he provide for his wife and small child? His home was already a place of homelessness. Technology could not answer for it. But a nurse was there. Was the nurse there in spite of the technology of medical care? In addition to that technology? With that

technology? In other ways? In the examples cited are the questions that ask for deeper understanding. What does it mean to be there, a nurse?

Second Reflection: On Themes of To Be There a Nurse

To Be There a Nurse is to Ease the Dis-ease of Illness

From one day to the next, the nurse participates in and often initiates the small changes which aid recovery. When the patient is lost in the complexity of previously simple tasks such as washing, dressing, eating, the nurse is there, doing for and with the patient what the patient cannot do. During such encounters, the nurse 'establishes rapport' with the patient. But the expression 'establishes rapport' belies the artfulness and skill of the nurse who helps a patient stand the second day after major surgery. The patient must will to stand with the nurse against the pain. The nurse sponsors a mutual endeavor, a mutual accomplishment.

To Be There a Nurse is to Remember that the Ill Person Feels Far From Home

Whether for diagnosis or treatment medical technology is formidable. The patient may feel like the junction of tubes and wires, the extension of a machine or even the target of a machine. Barbara Coleman describes her experience of cobalt treatments following brain surgery for a malignant tumor.

> The first time I took it the radiologist laid it on the line for me. He said, "you will go into a room with concrete walls and you will be bald for the rest of your life." I went into that concrete room. I was alone. Everything is operated by remote control. They transmit orders to you through an intercom. It was depersonalization at its zenith.[15]

Perhaps the radiation would kill only the cancer cells and the hair cells. What of the mind, the will, the emotions? The technology of medical care asks us, "Is life *that* precious?"

The technology of medical care must become routine for the nurse to carry out duties effectively. But the nurse must remember that the homeland of the heart gives meaning to technological care. The patient suffers technological care for the sake of the homeland of the

heart. The language of the heart is the simple sharing of anecdotes and news about family and friends, work, recreation, and worship. The nurse who is mindful of the homeland speaks the language of the heart. [16]

To Be There a Nurse is to See Pain in the Light of Hope

Hope is the nurse's promise of help, asserted in the greeting, "Good morning, I am your nurse today." Hope is the nurse's assurance that post-operative pain will pass. And hope is the nurse's presence when pain does not pass. Elizabeth Lord, a nurse who recovered from cancer, describes her relationship with Jean, who was dying of cancer. The light of hope she gave was not the promise of recovery but the presence of care. She gave herself.

> Jean has been here three weeks and now as I walk into her room, we don't say much... She received the last rites of the church a week ago and tells me so. We have talked about God and how to pray and why God has permitted this to happen. It is no longer simply a nurse-patient relationship; it is much more. She depends on me for reassurance, understanding, compassion, and, yes, even love.[17]

Has the nurse gone beyond what nursing is? What of the emotional stress, and the nurse's other responsibilities in hospital and at home? Has the nurse found what nursing is? What of these last days of life in a hospital room, and the earth and sky are beautiful, and memories glow with the warmth of life, and pain is everywhere? Will the nurse who gives herself find herself emptied or strengthened?

> I see her [Jean's] body lose its tension; she smiles and thanks me, says I have made her feel better, more relaxed about everything.[18]

A little kindness and compassion, and the face of pain relaxes for a moment in a smile, the voice from death whispers, "Thank you." A little kindness, a little compassion—a little light in the shadow of pain and death. And this light shines on the nurse, too. She receives the smile, the deep gratitude; she experiences wonder at the patient's courage and dignity. She gives from the heart and receives to the heart. Yes, also the grief. Where is the light in grief?

Notes

[1] See Martin Heidegger, *Being and Time,* trans. J. Macquarrie and E. Robinson (New York: Harper & Row, 1962).

[2] Cecil Woodham-Smith, *Florence Nightingale,* (Glasgow: William Collins & Sons Co., 1977), p. 185, biography; see also Florence Nightingale, *Notes on Nursing: What It Is and What It is Not,* (1869/1946 Montreal: Lippincott), instruction to student nurses.

[3] Responses to excerpts from *Notes on Nursing* were developed through dialogue with Shirley Wood, R.N. Nephrology and Dialysis, University of Alberta Hospital, Edmonton, Alberta, September 21 & 27, 1984.

[4] Ruth is a pseudonym. This example is reconstructed from interview notes.

[5] Wood, 1984.

[6] Wood, 1984.

[7] Jack is a pseudonym. This example is reconstructed from interview notes.

[8] Wood, 1984.

[9] Wood, 1984.

[10] Laura Copp, "The Spectrum of Suffering," *American Journal of Nursing, 74,*3 (1974), 495.

[11] Wood, 1984.

[12] Wood, 1984.

[13] Wood, 1984.

[14] Wood, 1984.

[15] Cited by Norman Cousins, *The Healing Heart,* (New York: W. W. Norton & Co., 1983), p. 149.

[16] I wish to thank Vangie Kelpin for helping me reflect on this theme.

[17] Elizabeth Lord, "My Crisis With Cancer," *American Journal of Nursing, 74,*4(1983), 649.

[18] Lord, p. 649.

Chapter IX

LORD TENNYSON: ONE WITHOUT THE OTHER

Reflections: On "In Memoriam," Themes of the Journey Through Grief

Tennyson wrote "In Memoriam, A.H.H."[1] as a tribute to Arthur Henry Hallam, his closest friend. The poem journeys through the experience of grief, the one without the other, from the early confusion, to acceptance, to peace, and even joy. First published in 1850, the poem led Queen Victoria to offer Tennyson the laureateship.

To Speak About Grief

Language fails to express grief.

I sometimes hold it half a sin
To put in words the grief I feel;
For words, like Nature, half reveal
And half conceal the soul within.

The "sorrow of language" writes Merleau-Ponty, is that words cannot express all we want to say. How can we convey our grief? Language lives; there are no words for death. And words do not mean the same to everyone. "Experiences of grief vary to such an extent that intended and interpreted meanings may be diametrically opposed."[2] For example, "It's all for the best," may sound callous though it is well meant. So we venture, "We're sorry... Is there anything we can do to help?" We respond, "You have done so much already." And we give and receive flowers or fruit, or a handshake, or a hug. We give ourselves in these conventional gestures. But we stay ourselves in these conventional gestures, too. We do not want to hurt those we meant to help.

Using language to alleviate grief.

But, for the unquiet heart and brain
A use in measured language lies;
The sad mechanic exercise,
Like dull narcotics, numbing pain.

We ponder the events that happened before death as if we could change the outcome. 'If only we had... How could we have... Perhaps we should have...' Late into the night we talk and in the morning, we rise with the same thoughts. Death is with us in the morning. We could not talk it through.

Language shelters grief.

In words, like weeds, I'll wrap me o'er,
Like coarsest clothes against the cold;
But that large grief which these enfold
Is given in outline and no more. (p. 122)

We wrap ourselves in words to protect us from the bitter cold of the grief in our soul. To grief belongs the silence of our life, the silence of days lived with the one who is gone. That great bulk of silent time is now a mist. Language begins to penetrate the mist: language is the path to "the Soul within." Language is also the path to the world outside. "We share grief with a devoted friend: this expression of grief in words and tears, gives release to the pain and anguish dwelling in the depths of our being."[3]

Gradually, the speaking turns from death to life. Recollections take on new meaning as treasures gathered from a way of living that have the name of the one we love. Gradually, too, the routines of daily life enfold us as we listen to friends chat about family, work, and weather. The language of friendship shelters our grief as we return to the workaday world.

Dark House

The house is the last vestige of friendship.

Dark house, by which once more I stand
Here in the long unlovely street,
Doors, where my heart was used to beat
So quickly, waiting for a hand,

A hand that can be clasp'd no more-
Behold me, for I cannot sleep,
And like a guilty thing I creep
At earliest morning to the door.

We go to the place of our memory but the house is dark. It was the hand of our friend that invited us into the house. But the hand of friendship is gone: "a treasured home; a barren house."[4] The Old Norse word for "home" is *heimr*, "residence," "world." Once this home embraced us in its world: we belonged here; but the "house"—Old English, *hús*, "shelter"—cannot shelter us from death.[5] The house stands empty for us. There is no one watching at the window, no one waiting at the door. No rush of greetings and silence and sudden laughter. "All that remain are silent photographs on the mantel."[6]

Bleakness engulfs us.

He is not here; but far away
The noise of life begins again,
And ghastly thro' the drizzling rain
On the bald street breaks the blank day.(p. 124)

"The cold harsh fact is that life goes on in the world as though nothing changed in our own private world."[7] There is a notice in the paper. A gathering of friends. A service in the church. We resume our workaday responsibilities. But we are estranged from the purposeful rhythm of daily life. Traffic lights blink red and green and people stop and go. The people stop and go. We have no reason to stop or go.

The Paradox of Calm

The silence of calm

Calm is the morn without a sound,
Calm as to suit a calmer grief,
And only thro' the faded leaf
The chestnut pattering to the ground;

The light of calm

Calm and still light on yon great plain
That sweeps with all its autumn bowers,
And crowded farms and lessening towers,
To mingle with the bounding main;

The air of calm

Calm and deep peace in this wide air,
These leaves that redden to the fall,
And in my heart, if calm at all
If any calm, a calm despair;

The rest of calm

Calm on the seas, and silver sleep,
And waves that sway themselves in rest,
And dead calm in that noble breast
Which heaves but with the heaving deep. (p.127)

Exhausted from the wild grief of the first days and nights, we wake to "still light," "deep peace," "and waves that sway themselves in rest." "All the qualities of calm in nature penetrate the entire human being. In nature, we find solace and companionship."[8] Standing thus in nature, we stand apart from nature when we ponder life and death, and we can respond to the silence, light, air and rest of calm with "calm despair" because of a "dead calm." "But is this a true 'calm'? Is there not always hope and faith as in living with the memory of love? Can someone who was loved and needed ever really leave our lives?"[9]

Sharing a Life

Sharing burdens:

I know that this was Life,—the track
Whereon with equal feet we fared;
And then, as now, the day prepared
The daily burden for the back.

You needed me;

But this it was that made me move
As light as carrier-birds in air;
I loved the weight I had to bear,
Because it needed help of Love;

I needed you.

Nor could I weary, heart or limb,
When mighty Love would cleave in twain
The lading of a single pain,
And part it, giving half to him. (p. 137)

The treasure of the days that are gone dwells, not in the ease of the days, but in the responsible work of the days, a work of love, shared in love, lightened by love. "During World War II," says Clara, "a poster commonly seen was that of a boy carrying a sickly younger boy. Above was the caption, 'He's not heavy, Mister. He's my brother.' Love carried the burden. In the same way, big sister helps little sister, as when our daughter carried her younger sister up the school stairs on her back after the other children were in class because of the bone pain the younger one suffered. It is always easier to be the one who can help than the one who needs

help."[10]

Immortal treasure

I hold it true, whate'er befall;
I feel it, when I sorrow most;
'Tis better to have loved and lost
Than never to have loved at all. (p. 138)

"To pass through life uncaring would be mere existence. To give love to a fellow being is to reflect the image of God."[11] Through the eyes of love, we see with William Blake, "the world in a grain of sand and eternity in an hour." The hour, like the grain of sand, holds the possibility of the universe. The possibility of the universe is meaningful to us as the possibility for the one we love. Our possibility blossoms when love constrains us to live for the other. Death does not end our cherished responsibility to live for the other.

If ye break faith with us who die
We shall not sleep. . .[12]

The life we shared is never lost though never found again.

Life Stops (The First Christmas After)

We are apprehensive

With trembling fingers did we weave
The holly round the Christmas hearth;
A rainy cloud possess'd the earth,
And sadly fell our Christmas-eve.

We pretend to be glad

At our old pastimes in the hall
We gamboll'd, making vain pretence
Of gladness, with an awful sense
Of one mute Shadow watching all.

Our circle is smaller

We paused: the winds were in the beech;
We heard them sweep the winter land;
And in a circle hand-in-hand
Sat silent, looking each at each.

The present seems to echo the past; it has no voice of its own

Then echo-like our voices rang;
We sung, tho' every eye was dim,
A merry song we sang with him
Last year; impetuously we sang.

We speak our loss

We ceased; a gentler feeling crept
Upon us: surely rest is meet.
"They rest," we said, "their sleep is sweet,"
And silence follow'd, and we wept.

We speak our hope

Our voices took a higher range;
Once more we sang: "They do not die
Nor lose their mortal sympathy,
Nor change to us, although they change;

Rise, happy morn, rise, holy morn,
Draw forth the cheerful day from night:
O Father, touch the east, and light
The light that shone when hope was born. (pp.139,140)

Christmas is celebrated as if it were the same Christmas as last year and the year before. But we cannot hide from our grief. Wherever we look, a treasured smile is missing. Whenever we speak, a treasured voice is gone. "With dismay, we cast a backward glance down the corridor of time. Our hope that the magic of Christmas could return to us our human treasures is a fleeting hope for a fleeting season."[13] Yet the Christmas celebration survives the loss of ones so greatly missed: a child was born in Bethlehem. "Hope is born at Christmas, and we move with a lighter step and new resolve into the unknown future."[14]

"Be Near Me"

Physical signs of death

Be near me when my light is low,
When the blood creeps, and the nerves prick
And tingle, and the heart is sick,
And all the wheels of being slow.

We sit beside the one we love, alert to the rhythm of breathing, the slightest movement, a momentary frown. We sit so near, yet so far away. We say over and over, "Where there is life, there is hope." We look for life. We wait for death.

Emotional signs of death

Be near me when the sensuous frame
Is rack'd with pangs that conquer trust;
And Time, a maniac scattering dust,
And Life, a Fury slinging flame.

Death takes time, and time is a "maniac." There is a moment that takes an hour, an hour that lasts a day, a day that is unending night. The clock no longer orders our life. We eat

lunch at midnight if we remember to eat at all. We stay where we are needed, and we need to stay.

Spiritual signs of death

Be near me when my faith is dry,
And me the flies of latter spring,
That lay their eggs, and sting and sing
And weave their petty cells and die.

What is the sum of our days? Even if we look, not to the vastness of eternity, but to the vastness of history, our life is nothing. Our life has meaning in this moment—always just past, always new—this moment that calls us to respond, like Martin Luther, "Here I stand. I cannot do otherwise."

The need for companionship

Be near me when I fade away,
To point the term of human strife,
And on the low dark verge of life
The twilight of eternal day. (pp.152,153)

"One of life's greatest sorrows is that of loneliness, reinforced by the plight of helplessness, as the body fails to function normally."[15] In the loneliness of our grief, we remember our death. Our "heart is sick," we are "rack'd with pangs," our "faith is dry." Our soul "cries out for the companionship of its Maker and for the nearness of loved ones."[16] "Be near me..."

Learning to Trust

Can what is evil or aimless yield good?

O, yet we trust that somehow good
Will be the final goal of ill,
To pangs of nature, sins of will,
Deflects of doubt, and taints of blood;

That nothing walks with aimless feet;
That not one life shall be destroy'd,
Or cast as rubbish to the void,
When God hath made the pile complete;

Is the end of knowledge the beginning of trust?

Behold, we know not anything;
I can but trust that good shall fall
At last—far off—at last, to all,
And every winter change to spring.

So runs my dream; but what am I?
An infant crying in the night;
An infant crying for the light,
And with no language but a cry. (p. 155)

What does 'trust' mean? The Old English word for trust, *tréowian*, means "to believe"; Old Norse, *traust*, means "confidence"; Old High German, *trôst*, means "fidelity."[17] We confidently believe that God is faithful: we trust. As we trust that every winter will change to spring, so we trust that the seasons of our human existence will change from faltering hope to vigorous new life. Yet hope wanes through times of waiting and enduring. "Our perplexity so often ends in a cry: 'what is man that thou art mindful of him, and the son of man that thou dost care for him?'"[18] We want to know life's purpose when so much we experience works at cross-purpose to the good. We know that day is the other side of night. We cannot come to fully know. We can come to fully trust.

To be Silent About Grief

Expressing praise is a vain show of grief

I care not in these fading days
To raise a cry that lasts not long,
And round thee with the breeze of song
To stir a little dust of praise.

The meaning of his life is in what he set out to do

Thy leaf has perish'd in the green
And, while we breathe beneath the sun,
The world which credits what is done
Is cold to all that might have been.

His greatness cannot be measured here

So here shall silence guard thy fame;
But somewhere, out of human view,
Whate'er thy hands are set to do
Is wrought with tumult of acclaim. (p. 168)

The one we love is wrapped in silence as we are wrapped in words. We ponder what he gave, what he would have given in time. We would praise him if words could express our debt of love and gratitude to him for being all he could be. But "words cannot re-create him.

Therefore, our silence, more eloquent than words, 'speaks' our loss."[19] Silence shines: silence shrouds. Silence is the voice of the dead.

Life Goes On (The Second Christmas After)

We live through grief

Who show'd a token of distress?
No single tear, no mark of pain -
O sorrow, then can sorrow wane?
O grief, can grief be changed to less?

Grief marks our soul, not our face

O last regret, regret can die!
No - mixt with all this mystic frame,
Her deep relations are the same,
But with long use her tears are dry. (p. 170)

Life appears to win over death. "Tears do not visibly flow. There are inward tears."[20] And softly spoken or gently thought, 'Here he opened the gift I gave him'; 'There she sang the Christmas songs.' Other Christmasses come so close. We cannot say how close the tears. For grief is not less than last Christmas. But the memories are gentler now, more "softly outlined."[21]

Eulogy

Song of Faith

Perplext in faith, but pure in deeds,
At last he beat his music out.
There lives more faith in honest doubt,
Believe me, than in half the creeds.

strong doubt;

He fought his doubts and gather'd strength,
He would not make his judgment blind,
He faced the spectres of the mind
And laid them; thus he came at length

strong faith;

To find a stronger faith his own,
And Power was with him in the night,
Which makes the darkness and the light,
And dwells not in the light alone,

strong commitment.

But in the darkness and the cloud,
As over Sinai's peaks of old,
While Israel made their gods of gold,
Altho' the trumpet blew so loud. (p. 189)

Words cannot express our debt of love and gratitude; yet, here, a eulogy, not to praise the end of his work, but to ponder the beginning. We must try to tell the meanings of a life so dear. 'He believed through doubt.' "The battles with doubt are part of the clarifying process in making harmony out of discord. The struggles endow strength and a clearer, stronger, truer faith, a faith that heeds the clarion call of the trumpet."[22]

Song of Hope

Ring out, wild bells, to the wild sky,
The flying cloud, the frosty light:
The year is dying in the night;
Ring out, wild bells, and let him die.

Ring out the old, ring in the new,
Ring, happy bells, across the snow:
The year is going, let him go;
Ring out the false, ring in the true.

Ring out the grief that saps the mind,
For those that here we see no more;
Ring out the feud of rich and poor,
Ring in redress to all mankind.

Ring out a slowly dying cause,
And ancient forms of party strife;
Ring in the nobler modes of life,
With sweeter manners, purer laws.

Ring out the want, the care, the sin,
The faithless coldness of the times;
Ring out, ring out my mournful rhymes,
But ring the fuller minstrel in.

Ring out false pride in place and blood,
The civic slander and the spite;
Ring in the love of truth and right,
Ring in the common love of good.

Ring out old shapes of foul disease;
Ring out the narrowing lust for gold;
Ring out the thousand wars of old,
Ring in the thousand years of peace.

Ring in the valiant man and free,
The larger heart, the kindlier hand;
Ring out the darkness of the land,
Ring in the Christ that is to be. (pp.198,199)

"Ring out, wild bells." The Old Year takes with it its own darkness. "We anticipate the New Year with a joy: 'I shall go to him, but he shall not return to me' because 'I know that my Redeemer lives.'"[23] And wild as our grief the wild bells ring! Strong as our hope the strong clappers strike! Free as the wind the free notes chime! Our grieving never ends: our hope is strong again: our love is freely bound. Wild and strong and free!

Notes

[1] Alfred, Lord Tennyson, "In Memoriam, A.H.H.," *Tennyson: Selected Poetry*, ed. H.M. McLuhan (New York: Holt, Rinehart & Winston, 1966), pp. 118-220.

[2] Responses to excerpts from "In Memoriam, A.H.H." were developed through dialogue with Mrs.Clara Olson, bereaved sister, daughter, wife and mother, October 23, 1982.

[3] Olson, 1983.

[4] Olson, 1983.

[5] Klein, *A Comprehensive Etymological Dictionary of the English Language*, (New York: Elsevier Pub. Co:, 1971), p. 350.

[6] Olson, 1983.

[7] Olson, 1983.

[8] Olson, 1983.

[9] van Manen, Personal communication, January, 1985.

[10] Olson, 1983.

[11] Olson, 1983.

[12] J. McRae, "In Flanders Fields," In *Canadian Anthology*, ed. C. Klink, (Toronto: Gage, 1966), p. 216.

[13] Olson, 1983.

[14] Olson, 1983.

[15] Olson, 1983.

[16] Olson, 1983.

[17] Klein, p. 786.

[18] Olson, 1983; see also Psalm8:4.

[19] Olson, 1983.

[20] Olson, 1983.

[21] Olson, 1983.

[22] Olson, 1983.

[23] Olson, 1983; see also I Samuel 12:23b. These words express King David's grief at the death of his infant son and his confidence of eternal life with God; see also Job 19:24.

Chapter X

THE GATHERING

Student of a Research Question

I am a student of the research question that characterizes phenomenological research, "What is life like?" This research question fills me with its urgency because it dwells in my life and asks me how I ought to live. I study, not to master the research question, but to live in it with understanding. Paradoxically, in my search to understand the research question, I must step away from it. My step away from the research question is reflection, not reflection that would build a structure for life, but reflection that would search for the structures — themes of life and give these themes a home in written language and in the lives of the readers. What has it been like for me to learn to reflect — read, interview, write — phenomenologically?

Researching Phenomenological Texts

As a student of a research question that is conditioned by my coming to ask it out of my life of dialysis, I have been committed to search for understanding in texts that are authored in a strong way. As in learning to speak a foreign language, I had to learn to think from the inside of the authors' textual expressions. I could not stop reading at points of difficulty. And since the enigmatic phrase dwells within the wholeness of the authors' work, I needed to continue to read. There is beauty in the enigmatic phrase. The glimmer of meaning. The recognition, "I have not thought this thought before." I want to understand! As I read and reflected, the enigmatic phrase became the apex of simplicity and clarity. I found life there and I sought to welcome the phrase and surround it with the writing that reflection upon it had sponsored. The phrase now spoke from within my writing, it belonged to my thought about the research question.

There is also the phrase that jumps out from the text, laden with meaning. We receive such a phrase as a discovery. It is the clear articulation of a thought that was not ready to be

written, inspiration for our writing.

The indented style of the longer quotation was meant to help show its meaning. Not only do I defer to the author's way of writing but I recognize life through the author's unique expression, and the life cannot be separated from the words. Also, I wanted to be understood as I had understood the quotation because I have my own words too: the quotation is part of my research 'biography', part of my tradition as a student of the research question, "What is life like?"

Yields of the Literary Texts

The excerpts were a gift from the literary authors, words from life that gave me insight into the life of illness. The authors stood within life to ask, "What is life?" through their writing of the life of one in community. The deep questioning of the uniqueness of the individual in community, love for the other personified, was a pathway for the research question, "What is life like?"

I searched for the words that enabled these authors — researchers of life, to write life. So I tried to speak with persons who shared my search for understanding, persons who speak with the wisdom that dedication to the other teaches.

As interviewers, we do not come with questions, our coming is a question. Our attitude is openness: each interview is different from the other, each person is unique. Yet my participation was guided by the expression of life in the literary text. The style of research writing was subject to the manner in which life was articulated through the interview in response to the literary text. For example, in **Ivan Ilyitch: One Against the Other Searches for the Other**, the death of Ivan Ilyitch 'speaks' as a parable of life in a technological society. The quality of parable was heightened by Rev. Dr. Leadbeater's sermon in response to the excerpts from ***The Death of Ivan Ilyitch*** and abides in the chapter as a sustained reference to Ivan, Vanya, he. Ivan Ilyitch is the example. However, in **Doctor Rieux: One For the Other**, I wrote as Doctor Ulan spoke, not of Doctor Rieux's life in ***The Plague***, but of Doctor Ulan's response

to his life, a comparison of thought and action in similar and differing medical situations. So the medical situation is the example. In **Florence Nightingale: One By the Other**, Nurse Shirley Wood responded to generalizations concerning nursing care that came from the heart of Miss Nightingale's experiences with wounded soldiers. Through Shirley's examples of her experiences of nursing care, she has brought these generalizations back to life. I wrote her examples as a living word. In **Pauline Erickson: One With the Other**, the responses to excerpts from Pauline's diary were the articulation of the meanings of my experiences of illness in a family where my brothers and sisters also had kidney failure. It is the writing of the years we shared, the love we shared, the we of illness. In **Lord Tennyson: One Without the Other**, my mother and I found it difficult to speak our grief, our response to "In Memoriam, A.H.H." This poem questions and cares for our silence in grief, the silence of the human being before the Creator. This silence belongs to the written word. Mother's written responses to the excerpts keep this quality of silence. We had few words for grief, and we could find no more.

Yields of the Writing

The other chapters asked for more words, for the further articulation of the central themes found in the First Reflection: Letting Go of the Things, The Struggle to Be Born into a Life of Illness, The Heart of Pity, To Be There a Nurse. In the First Reflection, I tried to journey with those who had experienced illness as Kierkegaard journeyed with Abraham in his writing. In the Second Reflection, I tried to respond to each journey thematically as Kierkegaard had responded to Abraham's journey with his expression of themes of faith. The action of journeying was thematized in the central thematic expressions, Letting Go of the Things and The Struggle to Be Born into a Life of Illness. Illness is an individual journey and the themes of illness became the themes of personal change in light of what never changes: logos. Reflection at the end of the journey was highlighted in the central thematic expressions, The Heart of Pity and To Be There a Nurse. Illness is a journey to the beginning and the themes of illness became the themes of a way of being in light of what never changes: logos.

The themes have been the strength of my journeys as a student of the research question, "What is life like?" But each journey has been a different history, so the way of expressing the themes for each journey has been different — yet there is unity to the thematic content. For example, when a journey of illness started with the question, "Why ought Ivan die?" , the thematic expressions were different than a journey that started with the question, "How is self-pity honorable?" However, these questions demonstrated a showing power in the lives of Ivan and Pauline as they lived through the questions to the place of rest. Such questions were given to me for research, questions that are always too difficult. How could anyone articulate the showing power?

All the work of phenomenological research is for the writing, and the writing is the most difficult work of all. The writing *is* the research rather than the report of research. For example, when I am alone, pen in hand and paper, there are no words unless I write them; there is no silence unless the words I write keep the silence. The writing is a way of reflection.

Phenomenological research writing is autobiographical in the sense that I want to understand more deeply what I have experienced so I can love life better. Writing my experience helps me reflect, reflecting on my experience helps me write. But because I reflect on my experience in dialogue with the thematic questions and other sources, I seldom write my experience as it happened but rather, I write the thought that my experience nurtured. For example, many expressions arise from my experience of dialysis in the early 1970s when the procedures and equipment were primitive and many friends suffered and died in the angst of too much technology and not enough technology. Those years at the dialysis unit are the words: " And when the pain does not pass, hope is the presence of care."

Phenomenology is research for living — *our* living. The thematic questions arising from my written response to one life are set in relief for my continued reflection by another life. For example, Pauline's question, "How is self-pity honorable?" remained to me an enigma until I read "I Thought I Was Too Young" by David Cornelius. David's description of his experience of illness helped me to articulate themes of self-pity which lead through the experience of

self-pity to the experience of blessings. The question I had doubted was the first step on a journey of hope with Pauline and David.

Reflecting on thematic difficulties in text helped me to find questions that open up the way through the difficulty. For example, The Heart of Pity is permeated with reflection on a thematic impasse I experienced during the First Reflection: one man wrote honestly that suffering defeats the doctor (Why suffering? Why defeat?); one man spoke honestly in response, "Suffering does not defeat the doctor" (Is this the absence of defeat or the refusal of defeat?). I began to understand the impasse as dialectic when I searched for the deep meaning of doctor there. The questions I found helped me journey to the heart of pity.

Listening to interviewees respond to my writing helped me to reflect on the adequacy of my expression in relation to their experience. For example, in Letting Go of the Things, Rev. Dr. Leadbeater helped me to reflect upon a thematic description I had written which was inadequate to express his experience of ministering to those who judged themselves condemned and therefore condemned others like themselves; but found God's mercy for themselves, and therefore, found the other. He said that the relation of self to others is like the relation of concave to convex in a glass bottle. There are no others in Ivan's experience of condemnation. The glass shatters. Others live in his experience of mercy. The thematic description for Judgment to Mercy was re-written through this reflection.

Writing to understand is learning to let the themes 'speak'. For example, I had chosen to write the thematic statements in sentences for the Second Reflection. The sentence expressed the fullness of the themes of Pauline's experience. But the themes of Ivan's experience 'expressed themselves' as A to B — terse and tentative, like Ivan's search.

Learning to write and writing to learn requires a place. More than a desk and chair and bookshelves, a place is openness to the new researcher and the new researcher's question; a place is the friendship of teaching and learning. In the manner of friendship, Dr. Ted Aoki, then Chairman of the Department of Secondary Education, welcomed me. In the manner of friendship, he showed me much of what my research could be, though seldom speaking directly

of it. In the manner of friendship, his manner, there was a place for silence, a place for question, a place for sharing: a place for me.

Learning to write and writing to learn require a teacher. I learned to write with the help of the teacher, Dr. Max van Manen, who had walked the path of the research question in his writing. Unlike the writing of people I have not known, his writing is a part of his living conversation with me. If I could write like that... But my writing was the central text for dialogue with the teacher concerning the content and style of writing, the pathway of further interviewing, reading and writing — the research of writing. He taught me to write myself. For example, the teacher asked me to write an example of what a chapter of research concerning illness might be like. I gave "Pauline's Diary"[1] to the teacher to read as a possibility for research writing concerning the life of illness. The teacher responded by giving me the writing of three phenomenologists; Heidegger, "On the Essence of Truth" and "The Origin of the Work of Art", Gadamer, "The Ontology of the Work of Art and Its Hermeneutic Significance", and Kierkegaard, *Fear and Trembling*. These sources became the content and structure for the research writing of Chapter IV, **The How of Understanding**. My writing, "Pauline's Diary" entered into the tradition of research and became articulate for me as a way for continuing research through the guidance of the teacher. He had journeyed that way — he could show me the way. Yet always, he asked me to find the way by writing.

Learning to write and writing to learn is blessed by the fellowship of other students of the research question who are involved in formal study or are learning from life in whatever situation. For example, students in the Faculty of Education and I have shared our research concerns and writing. We have found a common purpose in our different pursuits. Our research springs from our daily life for our daily life; we write because we want to give something good.

But how can I give something good unless I am in relationship with the One who is good? So prayer was an important part of my research. The thoughts I wrote are prayerful. Thought that comes from the heart of experience, which Gadamer calls pain, refers to the love that comes from God. As this love is the source of validity for our daily living, so it is the

source of validity for research. This one source of validity relates the researcher to the reader in dialogue: the researcher strives to write the love that the reader lives, and the reader strives to live in the love that the researcher articulates.

The Homecoming

Is there a name for logos? A person to whom we can turn when we begin a journey like Abraham? A person who will give us faith and teach us to live in faith? A person whose presence will transform the sacrifice into a blessing of hope and joy and peace? Name of logos — Word of God,[2] Jesus. I give my life to You.

A boy who had cerebral palsy attended Bible Camp where the other boys mimicked his movement, his speech. Each evening, one cabin was responsible for devotions for the entire assembly. The boys in his cabin chose him, to laugh again. He came, speaking haltingly, his words breaking under the awesome silence of each sacred breath, "I love Jesus and Jesus loves me." The assembly was silent. He had spoken, "not like the stranger or the guest, but like the child at home."[3] How can we ever hope unless we can always hope? I look to the cross and the empty tomb. My hope in illness and death is the comfort of my Creator's eternal love, embodied in the life of Jesus and in the lives of you who care. Let God make us in the image of His Son. This is our sacrifice of praise. And in the weariness and rigor of illness, we will learn to rest our souls like a child at home. We are children of God.

Notes

[1] "Pauline 's Diary" was the first draft of the First Reflection in Chapter VI.

[2] See John 1:1-19

[3] Words from a hymn.

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